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RESEARCH ARTICLE

# Knowledge, Attitudes, and Perceptions of Healthcare Providers Regarding Sickle Cell Disease and Its Newborn Screening in Mbuji-Mayi, DRC

**Chantal Kayemba Lukalu**[1] **Alain Mutombo Ngeleka**[1] **Benjamin Kasongo Kabulo**[1] **Olivier Mukuku**[2*] **Léon Tshilolo Muepu**[1] **Stanis Okitotsho Wembonyama**[3] **Pascal Tshindela Lutumba**[4] **André Kabamba Mutombo**[1] **Oscar Numbi Luboya**[2,3]

[1] Department of Pediatrics, Faculty of Medicine, Official University of Mbuji-Mayi, Mbuji-Mayi, DRC
[2] Institut Supérieur des Techniques Médicales de Lubumbashi, Lubumbashi, DRC
[3] Department of Pediatrics, Faculty of Medicine, University of Lubumbashi, Lubumbashi, DRC
[4] Department of Parasitology and Tropical Medicine, Faculty of Public Health, University of Kinshasa, Kinshasa, DRC

**Correspondence to:** Olivier Mukuku, Institut Supérieur des Techniques Médicales de Lubumbashi, Lubumbashi, Democratic Republic of the Congo; Email: oliviermukuku@yahoo.fr

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**Abstract: Background**: Sickle Cell Disease (SCD) remains a major public health issue in sub-Saharan Africa. Newborn screening (NBS) programs are crucial for early diagnosis and improved survival. However, their effectiveness depends largely on healthcare providers' knowledge, perceptions, and attitudes. This study assessed these aspects among providers in Mbuji-Mayi, Democratic Republic of the Congo. **Methods**: A cross-sectional analytical study was conducted among 191 healthcare providers selected by stratified random sampling. Data were collected using a structured questionnaire and analyzed with STATA version 16. Descriptive statistics were used to summarize participant characteristics. Bivariate and multivariate logistic regression analyses were performed to identify determinants associated with knowledge of SCD. **Results**: The median age of respondents was 29 years, with a predominance of females (71.20%). Most participants had a secondary or higher education level (97.38%) and were nurses (56.54%). About 76.44% had heard of SCD, mainly through television (64.38%) and radio (20.55%). Regarding attitudes, 74.66% believed in the importance of screening and supported early testing, while 98.95% favored referring newborns with SCD to hospitals. Perceptions revealed strong cultural beliefs: 82.20% associated SCD with mysticism or diabolical causes. Bivariate analysis showed that knowledge of SCD and its NBS was significantly associated with profession (crude OR = 36.30), prior examine SCD patients (crude OR = 36.00), and education level (crude OR = 14.15). In the multivariate model, two factors remained independently associated with adequate knowledge: being a medical doctor (adjusted OR = 23.382; 95% CI: 3.097–176.550; $p = 0.0022$) and having prior experience examining a patient with SCD (adjusted OR = 29.154; 95% CI: 3.584–237.150; $p = 0.0016$). **Conclusion**: While awareness of SCD among healthcare providers in Mbuji-Mayi is relatively high, significant misconceptions and cultural beliefs persist. Professional category and clinical experience with SCD are key determinants of knowledge. These findings highlight the need for targeted training and sensitization to strengthen early screening practices and address sociocultural barriers.

**Keywords:** Sickle cell disease, newborn screening, healthcare providers, DRC

## 1 Introduction

Sickle cell disease (SCD) is a hereditary hemoglobinopathy with global distribution, characterized by early-onset and debilitating clinical manifestations. It accounts for approximately 66.6% of all hemoglobinopathies diagnosed in newborns worldwide [1]. SCD is associated with significant morbidity and mortality, much of which is preventable through early diagnosis. Newborn screening (NBS) has proven to be a critical strategy for early detection, enabling timely management. In high-income countries, the implementation of systematic NBS programs has led to a dramatic reduction in disease prevalence, from 16% to less than 1% [2–4].

In sub-Saharan Africa, many newborns carrying the sickle cell trait or disease are born without a confirmed diagnosis. Yet, this region bears the highest burden of the disease. In the Democratic Republic of the Congo (DRC), prevalence rates have been reported as high as 2.3% for the homozygous SS genotype and up to 40% for the heterozygous AS genotype [5]. Various estimates indicate that the prevalence of SCD in sub-Saharan Africa ranges from 20% to 38%, with figures such as 1–28% in the Eastern Mediterranean region [1], 25% in Benin [2], 24–25% in Nigeria [3], and 18% in the DRC, including 7.1% SS and 10.9% AS genotypes [4, 5].

Regrettably, most cases are diagnosed only during painful vaso-occlusive crises, despite the fact that NBS could prevent such life-threatening complications. In the DRC, NBS remains in its infancy, especially in cities like Mbuji-Mayi where implementation is still embryonic and faces sustainability challenges. In this region, the neonatal mortality rate among children with SCD is estimated at 37.4% [6]. Indirect data further suggest that anemia-related mortality in Mbuji-Mayi is around 1.5% annually, with SCD accounting for up to 50% of these deaths before the age of five [3, 6].

Currently, curative treatment options for SCD, such as bone marrow transplantation and gene therapy, are virtually inaccessible in the DRC due to extreme poverty and the prohibitive costs associated with these advanced interventions [3, 4]. According to the World Health Organization (WHO), two levels of prevention strategies are essential: primary prevention to reduce disease incidence, and secondary prevention to reduce morbidity and mortality. At the secondary prevention level, NBS emerges as a crucial intervention in the Congolese context.

This preliminary study aims to assess the knowledge, perceptions, and practices of healthcare providers regarding SCD and its NBS in Mbuji-Mayi. Additionally, it seeks to evaluate the level of knowledge of SCD and its NBS, identify its key determinants, and explore the degree of community engagement and adherence to this public health strategy.

# 2 Materials and methods

## 2.1 Study design and setting

This research was designed as a cross-sectional and multicenter study. It was conducted over a period of six months, from January 1st to July 4th, 2022, in the city of Mbuji-Mayi, located in the south-central region of the DRC. Mbuji-Mayi is a highly populated urban area known for its limited access to specialized healthcare services, particularly for chronic diseases such as SCD. The urban health zones selected for this study were chosen due to their high pediatric patient load and the presence of care facilities involved in maternal and child health.

This study aimed to evaluate the knowledge, perceptions, and practices of key stakeholders regarding SCD and NBS. Three main groups were targeted: 1) parents or guardians of children diagnosed with SCD; 2) healthcare providers working in pediatric or general medicine, and 3) community health workers (CHWs) actively engaged in health education and promotion within these health zones.

## 2.2 Eligibility criteria

Participants were recruited based on specific inclusion criteria. Eligible individuals included:
(1) Heads of households who had resided in Mbuji-Mayi for more than two years;
(2) Healthcare professionals currently providing pediatric or related clinical services;
(3) CHWs involved in outreach, screening, or education activities related to maternal and child health.

All eligible participants were invited to take part in the study voluntarily after providing informed consent. Individuals who did not meet the residency criteria, were under the age of 18, or declined participation were excluded from the sample.

## 2.3 Sample size determination

The sample size was estimated using the Epi Info™ version 7.2 software, taking into account an anticipated prevalence of 40% for homozygous sickle cell disease (SS genotype), a margin of error of 7%, and a confidence level of 95%, assuming a simple random sampling model (no design effect). Based on these parameters, the minimum required sample size was 191 respondents. To account for possible non-responses or incomplete data, a total of 300 questionnaires were distributed across the study zones. After collection and quality control checks, 191 questionnaires were deemed complete and valid for statistical analysis, thus meeting the calculated minimum requirement.

## 2.4 Data collection procedures

Data were collected using a semi-structured, closed-ended questionnaire developed by the research team. The questionnaire was administered through face-to-face interviews conducted by trained field investigators fluent in the local languages. The questionnaire captured data on:

(1) Sociodemographic characteristics (age, gender, education level, occupation, *etc.*);
(2) Knowledge and perceptions about SCD and NBS;
(3) Healthcare practices and community health behaviors;
(4) Knowledge of SCD and its NBS.

All data collection was conducted in French. To ensure accuracy and consistency, all responses were initially transcribed in French and then translated into English when necessary, before undergoing a thorough coding process and statistical analysis.

## 2.5 Data analysis

Data were analyzed using Stata version 16, a robust statistical software widely used in epidemiological and public health research. Descriptive statistics (frequencies, percentages, means, and standard deviations) were used to summarize the characteristics of the study population.

For bivariate analyses, associations between categorical variables were evaluated using Pearson's Chi-square test. Odds ratios (ORs) and their corresponding 95% confidence intervals (CIs) were calculated to assess the strength and direction of associations between explanatory variables and the Knowledge of SCD and its NBS. Variables with a p-value $\leq$ 0.05 in the bivariate analysis were subsequently included in a multivariate logistic regression model to control for potential confounding factors and identify independent predictors of Knowledge of SCD and its NBS. Adjusted odds ratios (aORs) with 95% CIs were reported for the multivariate analysis, and a p-value $\leq$ 0.05 was considered statistically significant throughout the study.

## 2.6 Ethical considerations

This study was conducted in accordance with ethical standards governing human subjects research. The protocol received approval from the Ethics Review Committee of the Official University of Mbuji-Mayi. All participants were informed about the study objectives, procedures, and their rights, including confidentiality and the freedom to withdraw at any time without any consequence. Written informed consent was obtained from all participants prior to enrollment.

# 3 Results

## 3.1 Univariate analysis

A total of 191 respondents were included in the final analysis. The median age of the participants was 29 years, with an interquartile range from 26 to 33 years. The majority of respondents were female (71.20%), while males represented 28.80%.

In terms of educational attainment, the respondents were generally well-educated, with 97.38% having completed secondary or higher education. Regarding professional categories, nurses and CHWs represented the majority (56.54%), followed by medical doctors (35.08%), and a small proportion were categorized as other healthcare workers or CHWs.

From a religious affiliation perspective, Catholics accounted for 77.49% of participants, Protestants for 16.23%, and individuals from other religious backgrounds made up 6.28% of the sample (Table 1).

Table 2 provides a detailed summary of respondents' knowledge regarding NBS for SCD, the main sources of information, their attitudes toward screening, community perceptions of the disease, and opinions on preventive measures and the perceived importance of NBS. Awareness of SCD and its NBS was relatively high: 76.44% of respondents reported having heard of SCD and its NBS through various media sources, primarily television (64.38%) and radio broadcasts (20.55%).

In terms of perceptions regarding SCD, respondents held diverse views:
(1) 54.11% considered SCD a serious and dangerous disease not to be neglected.
(2) 22.60% described it as a deadly or life-threatening illness.
(3) 82.20% associated it with diabolical origins or mysticism, while 11.52% viewed it as a spiritual or supernatural affliction.

Preventive practices were also explored:
(1) 74.66% of participants recommended prenuptial testing as a strategy to prevent the disease.
(2) In the event of a positive test of NBS, 98.95% agreed on the importance of immediate referral to a hospital for early management.

(3) 67.02% discouraged marriage between couples identified as genetically at risk of transmitting the disease.

(4) 74.66% of healthcare providers expressed awareness of the significance of NBS for SCD and advocated for early screening—preferably at birth or within the first 7 days of life, using the Guthrie test.

**Table 1** Univariate Analysis of Respondent Characteristics (N = 191)

| Variables | Number | Percentage | 95% Confidence Interval |
|---|---|---|---|
| Gender | | | |
| Female | 136 | 71.20 | [64.22 – 77.51] |
| Male | 55 | 28.80 | [22.49 – 35.78] |
| Education level | | | |
| Primary | 5 | 2.62 | [0.86 – 6.00] |
| Secondary | 74 | 38.74 | [31.80 – 46.05] |
| Higher and university | 112 | 58.64 | [51.30 – 65.70] |
| Profession | | | |
| Nurse | 108 | 56.54 | [49.20 – 63.69] |
| Doctor | 67 | 35.08 | [28.33 – 42.30] |
| Community health worker | 16 | 8.38 | [4.86 – 13.25] |
| Religion | | | |
| Catholic | 148 | 77.49 | [70.90 – 83.20] |
| Protestant | 31 | 16.23 | [11.30 – 22.24] |
| Muslim | 10 | 5.24 | [2.54 – 9.42] |
| Non-believer | 2 | 1.04 | [0.13 – 3.73] |
| Type of Facility | | | |
| Health center | 96 | 50.26 | [42.95 – 57.56] |
| Referral health center | 79 | 41.36 | [34.30 – 48.70] |
| General referral hospital | 16 | 8.38 | [4.86 – 13.25] |
| Facility ownership | | | |
| Public | 30 | 15.71 | [10.86 – 21.66] |
| Private | 161 | 84.29 | [78.34 – 89.14] |

**Table 2** Knowledge, sources of information, attitudes, community perceptions, and opinions of respondents regarding newborn screening for sickle cell disease (N=191)

| Variables | n (%) | 95% CI |
|---|---|---|
| Knowledge of SCD and its NBS | | |
| Good | 146 (76.44%) | [69.77 – 82.27] |
| Poor | 45 (23.56%) | [17.73 – 30.23] |
| Source of information | | |
| School education | 7 (4.79%) | [1.95 – 9.63] |
| Health facilities | 15 (10.27%) | [5.87 – 16.38] |
| Radio | 30 (20.55%) | [14.31 – 28.02] |
| Television | 94 (64.38%) | [56.04 – 72.13] |
| Attitude towards NBS | | |
| Undergo screening | 23 (15.75%) | [10.26 – 22.69] |
| Consider it a serious disease | 79 (54.11%) | [45.67 – 62.28] |
| Believe it's a deadly disease | 36 (22.60%) | [16.10 – 30.25] |
| Aim to prevent disease | 11 (7.53%) | [3.82 – 13.08] |
| Community perceptions of SCD | | |
| Disease caused by ignorance | 7 (3.66%) | [1.49 – 7.41] |
| Diabolical disease | 157 (82.20%) | [76.02 – 87.35] |
| Incurable disease | 5 (2.62%) | [0.86 – 6.00] |
| Spiritual disease | 22 (11.52%) | [7.36 – 16.92] |
| Means of prevention | | |
| Through prenuptial testing | 189 (98.95%) | [96.27 – 99.87] |
| Treat after NBS | 2 (1.05%) | [0.13 – 3.73] |
| Perceived importance of NBS | | |
| Detect the disease | 109 (74.66%) | [66.80 – 81.49] |
| Prevent the disease | 37 (25.34%) | [18.51 – 33.20] |

**Notes:** 95 CI: 95% confidence interval; %: percentage; n: number; NBS: newborn screening; SCD: sickle cell disease

## 3.2 Bivariate analysis of factors associated with knowledge of SCD and its NBS

The bivariate analysis revealed several key factors significantly associated with participants' knowledge of SCD and its NBS (Table 3):

(1) Professional occupation was highly associated with knowledge of SCD and its NBS. Compared to medical doctors, nurses and CHWs were 36.30 times more likely to be familiar with SCD and its NBS and its importance (crude OR = 36.30; 95% CI: 4.87–270.58; $p < 0.001$).

(2) Personal experience with SCD significantly influenced awareness. Respondents who had previously examined a patient with SCD were 36 times more likely to be knowledgeable about SCD and its NBS (crude OR = 36.00; 95% CI: 7.819–165.75; $\mathrm{p} < 0.001$).

(3) Education level also played a crucial role. Participants with a secondary or higher level of education were 14.15 times more likely to understand and value SCD and its NBS compared to those with only primary education (crude OR = 14.15; 95% CI: 1.54–130.07; $p = 0.0026$).

**Table 3** Factors associated with knowledge of SCD and its NBS

| Variables | Good Knowledge (n = 146) | Poor Knowledge (n = 45) | OR [95% CI] | *p*-value |
|---|---|---|---|---|
| Age | | | | |
| 20–27 years | 55 (79.71%) | 14 (20.29%) | Reference | |
| > 27 years | 91 (74.59%) | 31 (25.41%) | 0.747 [0.366 – 1.527] | 0.423 |
| Gender | | | | |
| Female | 99 (72.79%) | 37 (27.21%) | Reference | |
| Male | 47 (85.45%) | 8 (14.55%) | 2.196 [0.949 – 5.083] | 0.062 |
| Educational Level | | | | |
| Primary | 1 (20.00%) | 4 (80.00%) | Reference | |
| Secondary/University | 145 (77.96%) | 41 (22.04%) | 14.15 [1.54 – 130.07] | 0.0026 |
| Religion | | | | |
| Muslim/Non-believer | 9 (75.00%) | 3 (25.00%) | Reference | |
| Catholic/Protestant | 137 (76.54%) | 42 (23.46%) | 1.087 [0.281 – 4.201] | 0.903 |
| Profession | | | | |
| CHWs/Nurses | 80 (64.52%) | 44 (34.48%) | Reference | |
| Physicians | 66 (98.51%) | 1 (1.49%) | 36.30 [4.87 – 270.58] | <0.001 |
| Having examined a patient with SCD | | | | |
| No | 2 (11.76%) | 15 (88.24%) | Reference | |
| Yes | 144 (82.76%) | 30 (17.24%) | 36.00 [7.82 – 165.75] | < 0.001 |

**Notes:** CHW: community health worker

## 3.3 Multivariate logistic regression analysis

After adjusting for potential confounders through multivariate logistic regression, two variables remained independently and significantly associated with knowledge of SCD and its NBS (Table 4):

(1) Professional occupation continued to be a strong determinant. Compared to nurses and CHWs, medical doctors were significantly more likely to have a good understanding of SCD and its NBS, with an adjusted odds ratio of 23.382 (95% CI: 3.097–176.550; $p = 0.0022$).

(2) Having previously examined a patient with SCD was also independently associated with better knowledge of SCD and its NBS. Respondents who had experienced such cases were nearly 29 times more likely to understand of SCD and its NBS (adjusted OR = 29.154; 95% CI: 3.584–237.150; $p = 0.0016$).

In contrast, gender and education level, although significant in bivariate analysis (for education), did not retain statistical significance in the multivariate model. This suggests that their apparent associations may have been confounded by other variables such as professional role or experience with SCD patients.

**Table 4** Multivariate analysis of factors associated with knowledge of SCD and its NBS

| Factors | Adjusted OR [95% CI] | *p*-value |
|---|---|---|
| Gender (Male *vs* Female) | 1.740 [0.644 – 4.702] | 0.2752 |
| Education (Secondary/University *vs* Primary) | 0.369 [0.018 – 7.477] | 0.5159 |
| Profession (Physician *vs* CHW/Nurse) | 23.382 [3.097 – 176.550] | 0.0022 |
| Having examined a patient with SCD (Yes *vs* No) | 29.154 [3.584 – 237.150] | 0.0016 |

# 4 Discussion

Since the development of the Guthrie test in 1963 by Robert Guthrie, SCD screening has been the subject of extensive research, particularly in several African countries where the prevalence of the disease remains high [2,6–9]. In the DRC, few studies have addressed this issue, with some conducted in Kinshasa and Lubumbashi [2, 3, 7, 8, 14]. Among these, the acceptability of NBS has rarely been at the center of investigation. In Mbuji-Mayi, NBS is still in its infancy and has struggled to gain a lasting foothold. A likely unknown number of children with SCD die within communities or healthcare facilities without ever being diagnosed, treated, or appropriately managed. To address this gap, the present study was conducted to improve knowledge, perception, and acceptability of NBS in a region where the disease remains largely neglected.

Moreover, this study highlights the urgent need to implement a comprehensive NBS program across all healthcare facilities in the city to ensure community participation and engagement, an essential prerequisite for the sustainability and success of NBS in Mbuji-Mayi [5, 14].

Assessment of public knowledge and practical attitudes toward SCD and its NBS has rarely been studied in the DRC since 2008. To the best of our knowledge, only a few such studies exist [2, 3, 7, 11, 14]. Some respondents in our study held misconceptions about the disease, describing it as incurable (3.66%) or attributing it to ignorance (2.66%). Alarmingly, 11.51% of respondents associated sickle cell disease with satanic or mystical forces, evil spirits, or curses inflicted on couples whose children were affected. Such beliefs can fuel stigma and depression, as described by several other authors [15, 16].

In many African contexts—and particularly within Congolese society—a segment of the population tends to rely on supernatural explanations for illness and death, including for sickle cell disease. This narrative has also been reported in Kenya by Marsh et al. in 2011 [22], and similar findings were observed in Mbuji-Mayi (Table 2).

It is therefore imperative for intellectuals, experts, and health professionals at all levels to engage in assertive advocacy through widespread sensitization campaigns and cross-sector collaboration, potentially even using artificial intelligence, to debunk these harmful beliefs and foster a culture of trust and positive perception. Odunvbun et al. in Nigeria demonstrated this effectively, achieving an NBS acceptance rate of 99.7% [23].

In our study, few participants knew their sickle cell status, despite Mbuji-Mayi being recognized as a high-prevalence area for SCD [2–4, 9]. This finding clearly points to a lack of routine screening programs in this region. Knight et al. [20] emphasized the importance of mass awareness and increased knowledge of sickle cell status as critical factors in advancing public health efforts to combat SCD. Sensitization is therefore essential, not only to convey accurate knowledge about the disease and the value of its NBS, but also to dismantle misinformation and break cultural taboos surrounding screening (Table 2).

Our findings indicate that knowledge of SCD and its NBS was not associated with age or gender (Table 4). While this aligns with Katamea et al.'s findings in Lubumbashi [8], it contradicts a Nigerian study by Nnodu et al. (2018) [21], which found that respondents aged 18–21 were more supportive of NBS [21]. These Nigerian participants had better knowledge of the disease, largely through education and media, and a greater awareness of its severity and complications, which led to their embracing NBS as an effective public health strategy for reducing SCD-related morbidity and mortality.

Regarding gender, women in our study were more likely to know SCD and its NBS than men. In the socio-cultural context of Mbuji-Mayi (predominantly Luba Bantu and pro-natalist), as in many Bantu communities, women are generally more involved in and concerned with the health of their children. From conception through adulthood, they are the primary caregivers and tend to be more sensitive and responsive to health issues. They are therefore more likely to accept interventions such as NBS or any treatment perceived as beneficial to their children's wellbeing.

Religious affiliation was a central focus of our analysis, given the high level of religiosity in Mbuji-Mayi, where evangelical churches proliferate throughout the city. Our findings showed that compared to non-believers, Muslims, and Pentecostals, Catholic and Protestant participants were more likely to know SCD and its NBS, though not voluntary termination of pregnancy, which they considered a grave sin and violation of the fifth commandment. Muslim and other respondents showed lower levels of knowledge, while Kimbanguists and members of revivalist churches were often less vocal and sometimes abstained from participation, adhering to the ethical principle of informed consent.

These findings are consistent with those of Katamea et al. and Nnodu et al., who also reported lower NBS acceptance among Muslim respondents [8, 21]. We believe this may be due to the growing requirement in many Christian denominations (Catholic, Orthodox, Pentecostal, Protestant) for couples to undergo prenuptial screening, including hemoglobin electrophoresis, before marriage. This is a commendable initiative and a missionary effort that deserves institutional support. A legislative framework to this effect would be welcomed and should prompt lawmakers to strengthen the Congolese Family Code accordingly. Furthermore, it is crucial to intensify community mobilization efforts and engage opinion leaders, pastors, and religious actors to promote the benefits of both prenuptial and NBS in high-risk areas such as Mbuji-Mayi.

In high-income countries, NBS programs supported by regular follow-up and specialized care have reduced sickle cell morbidity from 16% to less than 1% [2, 14, 24]. In contrast, in resource-limited settings like ours, many children with SCD remain undiagnosed, untreated, and poorly managed due to the absence of routine screening. NBS remains, in our view, an essential and lifesaving strategy. The DRC, and particularly Mbuji-Mayi, is no exception. In light of these findings, we urge policymakers and partners to prioritize the implementation of a national policy of NBS and comprehensive SCD care. This constitutes an urgent public health message that must be widely disseminated to all stakeholders to ensure affected children receive appropriate lifelong care in specialized pediatric settings.

As a preliminary investigation, this study had several limitations. Notably, the sampling did not allow for precise estimates, as reflected in the relatively wide confidence intervals. Additionally, the qualitative data were analyzed primarily through a quantitative lens.

Further research is therefore needed, including fully qualitative studies conducted before and after NBS implementation in both urban and rural settings, cost-effectiveness analyses, and impact assessments in terms of lives saved. These future studies will provide deeper insights into the acceptability and effectiveness of NBS programs in our context.

# 5 Conclusion

This preliminary study indicates that awareness of SCD and willingness to adopt preventive measures, such as premarital screening and systematic NBS, are generally satisfactory. These attitudes are significantly shaped by participants' occupations and their prior experience with examining a patient affected by SCD. Nevertheless, several challenges that could hinder the implementation and effective integration of NBS for SCD were identified. These findings underscore the urgent need to intensify community awareness, health education, and advocacy efforts to foster public engagement and ensure the early detection and management of affected children.

# Conflicts of interest

The authors declare that they have no conflict of interest.

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