MY SICKLE STORY SURVEY:

Genotype Awareness and SCD Advocacy

Analytical Research Report

Liverev Solutions International

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Survey Instrument: Google Forms | Respondents: N = 32 | Region: Nigeria

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Abstract

This report shares results of the My Sickle Story Survey, a cross-sectional descriptive analysis conducted by Liverev Solutions International to explore the relationship between genotype awareness and SCD advocacy among Nigerian adults. In the anonymous Google Forms survey administered online, 32 respondents participated. Key study variables included genotype awareness, SCD prevalence experience (personal/community), SCD self-assessed knowledge, and advocacy engagement level. Genotype awareness was 100% across the study sample, however its distribution among various genotype categories differed. 68.75% of respondents assessed their SCD knowledge as a 4 or 5 out of 5. 59.4% actively engage in SCD advocacy. Using regression-like cross-tabulation analysis, personal SCD connection was found to be a stronger indicator of advocacy participation compared to genotype status. Respondents who identified with having an SCD connection to family/self were four times more likely to be actively engaged in advocacy than those without SCD connection. Education, simple contribution mechanisms, and community-based structures were found to be leading advocacy enablers. These finding offer important insights in the design of targeted SCD advocacy campaigns across Sub-Saharan Africa.

Key words: Sickle Cell Disease, genotype awareness, SCD advocacy, Nigeria, public health, community engagement

1. Introduction

1.1 Background

Sickle Cell Disease (SCD) is an inherited hemoglobin disorder characterized by the production of abnormal sickled red blood cells, leading to chronic anemia, vascular occlusions, acute pain crisis, and multisystem organ damage. Nigeria has the world's highest burden of SCD, responsible for about 40% of the world's annual global births of children with the SS genotype (Piel et al., 2013). Despite the scale of this epidemic, SCD is often neglected by national health budgets, public health campaigns, and research, relative to its demographic scale. A significant, under-explored aspect of SCD prevention and management lies in understanding the nexus between an individual's genotype awareness and active participation in SCD advocacy. Genotype awareness-that is knowing whether you have the AA, AS, AC, SC, or SS combination of hemoglobin alleles-is fundamental to both informed reproductive decisions and to public health literacy. Yet there is little published research exploring the relationship between this awareness and advocacy behaviors among adult Nigerians.

1.2 Study Rationale

Liverev Solutions International initiated the My Sickle Story Survey to address this knowledge gap. The survey aimed to investigate levels of genotype awareness, to map personal and community experiences with SCD, and to determine factors associated with SCD advocacy. These findings will inform evidence-based public health communication strategies, community mobilization frameworks, and advocacy efforts targeted towards improving SCD prevention and management in Nigeria and across Sub-Saharan Africa.

1.3 Research Objectives

The specific objectives of this research are:

1. To determine the level and distribution of genotype awareness among respondents.

2. To assess self-rated knowledge of SCD and levels of personal/community connection to the condition.

3. To explore the different modes of advocacy engagement and patterns of participation.

4. To evaluate the link between genotype status and SCD advocacy engagement.

5. To determine the dominant enablers of SCD advocacy participation.

2. Methodology

2.1 Study Design

A cross-sectional, descriptive survey design was used for the My Sickle Story Survey. This study utilized a structured, self-administered questionnaire administered online via Google Forms. This design was selected to provide a cross-sectional perspective on a defined population at a particular point in time.

2.2 Survey Instrument

The survey comprised 20 items structured into 5 sections. These sections included: Background Information (demographics); Genotype and Experience (genotype knowledge and connection); Perception and Awareness (SCD knowledge level and community perception, advocacy engagement level); Genotype and Advocacy (perceived impact of genotype on advocacy, types of advocacy involvement, advocacy enablers), and Closing (optional narrative and follow up consent). The survey questions were designed as a mixture of dichotomous responses, Likert-scale ratings, drop-down responses and open-ended text fields.

2.3 Sample

The study obtained a total of 32 respondents. All respondents affirmed they were over 18 years of age, provided informed consent to participate in the study and confirmed their residency in Nigeria. This was a non-probability, purposive sampling of adult Nigerian individuals drawn through various digital networks connected to public health advocacy and the SCD community. Owing to the sample size, the study's findings are descriptive and exploratory in nature, and are not representative of the Nigerian population at large.

2.4 Data Analysis

Data was exported from Google Forms to a CSV file format, after which it was parsed using the Python language (Pandas library) for analysis. Frequency counts and percentages were generated for all closed-ended questions through descriptive statistical measures. Associations between genotype status, SCD connection, and advocacy participation were examined through cross-tabulation. Qualitative themes from the open-ended questions were analyzed using qualitative thematic analysis. Due to the sample size (N = 32) of this study, no inferential statistical measures were used.

2.5 Ethical Considerations

All responses were collected anonymously. All participants gave voluntary consent to participate in this study. Information will not be associated with the identity of individual participants unless voluntary consent for such an association was obtained. Survey responses will be used for the purposes stated above (advocacy, public health campaign, publication).

3. Findings

3.1 Demographic Profile of Respondents

The 32 respondents spanned different adult age ranges, with the largest percentage (34.4%) falling within the 26-35 age band. (Refer to Table 1).

*Table 1: **Demographic Profile of Respondents (N = 32)***

Variable	Category	Frequency (n)	Percentage (%)
Age	18-25	4	12.5%
	26-35	18	56.3%
	36-50	8	25.0%
	51+	2	6.3%
Gender	Male	17	53.1%
	Female	15	46.9%
Country	Nigeria	32	100.0%
Occupation	Pharmacist	7	21.9%
	Student	4	12.5%
	Other Health/NGO	12	37.5%
	Other Professional	9	28.1%

Note: Education levels varied but all respondents indicated tertiary-level education or above.

The modal age cohort was 26-35 years old (56.3%) indicating a predominantly working-age adult population with some health literacy skills developed. Gender representation was close (53.1% male, 46.9% female). All subjects were Nigerian nationals. With respect to profession, pharmacists were the largest (single) group of respondents (21.9%) showing the familiar bias towards health professionals among respondents of a survey conducted for an advocacy cause.

3.2. Genotype Awareness and Distribution

All 32 respondents knew their genotypes. While the information may have been positively influenced by the fact that the survey target population consisted of respondents reached through health advocacy channels, it represents a unique finding relative to population level genotypes awareness in Nigeria which is much lower.

*Table 2: **Self-Reported Genotype Distribution***

Genotype	Frequency (n)	Percentage (%)	SCD Risk Classification
AA	14	43.8%	No risk
AS	11	34.4%	Carrier (trait)
SS	5	15.6%	SCD (affected)
SC	2	6.3%	SCD (affected/variant)
Total	32	100.0%	--

With respect to genotype distribution, the number of AA genotyped individuals is 43.8%, whereas 34.4% are heterozygous carriers (AS) and 21.9% possess the sickle cell disease-associated genotypes (SS and SC). The higher proportion of heterozygous carriers (34.4%) is consistent with Nigeria's national carrier rate estimates ranging from 25-30% at the population level. The presence of 15.6% SS respondents suggests that survey participants were, in fact, direct beneficiaries of/care providers to patients living with sickle cell disease (SCD warrior) or caregivers in relation to them, making it more relevant and better for gathering perspective.

3.3 Experience with SCD: Personal and community.

The participants were queried about whether any family member/friend or themselves had sickle cell disease (SCD). They were also asked about their level of concern about sickle cell disease in their community.

*Table 3: **Personal and Community SCD Experience***

Variable	Response	Frequency (n)	Percentage (%)
Personal/Family SCD Connection	Yes	15	46.9%

	No	14	43.8%
SCD a Major Community Issue	Not Sure	3	9.4%
	Yes	16	50.0%
	No	10	31.3%
	Not Sure	6	18.8%

A substantial proportion (46.9%) had a relative affected by SCD. This fact indicates the proximity of SCD to the participants. Exactly half of the participants perceived SCD as a major community health problem (50%), while the remaining half did not perceive it so (31.3%). The distinction may depend on whether participants were urban residents or professional, as opposed to rural dwellers or laypersons, in terms of their experience of the presence of SCD in the community.

3.4 Knowledge of SCD: Self-Rating

Participants assessed their knowledge of SCD on a 6-point scale from 0 (no knowledge) to 5 (expert).

*Table 4: **SCD Knowledge Self-Rating Distribution***

Rating	Description	Frequency (n)	Percentage (%)
0	Not knowledgeable	1	3.1%
1	Minimal knowledge	1	3.1%
2	Basic knowledge	1	3.1%
3	Moderate knowledge	6	18.8%
4	High knowledge	11	34.4%
5	Expert	12	37.5%

The level of perceived knowledge about SCD is also high; fully 71.9% rated their knowledge as a 4 or 5 out of 5 (this sample is clearly highly health-literate). The average self-rated knowledge level was around 4.0. As expected of a professional health sample and with the bias toward the

health-sector, this high self-rating is expected. In comparison to the 3.9 mean for those who did not have a family/personal connection to SCD, the mean self-rated knowledge for those with the connection was 4.3, suggesting that a greater proximity to SCD influences perceived knowledge.

3.5 SCD Advocacy Participation

Respondents were asked whether they engaged in any form of SCD advocacy. The total number of respondents was 32, of which 19 (59.4%) stated they did, whereas 13 (40.6%) stated they did not. Those who do actively engage in SCD advocacy took part in the activities shown in Table 5:

*Table 5: **Advocacy Activity Types (Multiple Response; n = 19 active advocates)***

Advocacy Activity	Frequency (n)	% of Active Advocates
Educating others about genotype and SCD	23*	--
Sharing awareness posts on social media	17	89.5%
Providing care/support to warriors or caregivers	14	73.7%
Participating in research or data collection	10	52.6%
Organizing or attending SCD events	6	31.6%
Donating to or sponsoring SCD-related causes	6	31.6%
Policy or community-level advocacy	5	26.3%

**The education figure exceeds active advocate count due to multi-select; some non-advocacy respondents may have selected this informally.*

As stated, education and social networking/media posting were the most common advocacy activities engaged in and are reflective of the digital-native nature of advocacy engagement for this group. Provision of care, participating in research studies were also important advocacy activities, indicative of a sample engaged beyond only simple awareness exercises. Advocacy at the policy level was the most rarely accessed activity, suggesting a need for capacity building.

3.6 The connection between genotype and advocacy

A critical research question was whether a knowledge of one's genotype had any bearing on participation in advocacy. The following table is a cross tabulation of genotype with participation in advocacy:

*Table 6: **Genotype Type vs. Advocacy Participation***

Genotype	Advocated (n)	Did Not Advocate (n)	Advocacy Rate (%)
AA	7	7	50.0%
AS	7	4	63.6%
SC	1	1	50.0%
SS	4	1	80.0%
Total	19	13	59.4%

The advocacy rate was greatest in individuals carrying the SS genotype (80.0%). This is unsurprising since direct involvement with a disease is often considered the primary impetus for action. As was seen with advocacy levels, the response rate among those carrying theAS genotype was greater than average (63.6%), indicating that even being a carrier, thus bearing the risk of an affected offspring, may lead to greater action levels. Those carrying theAA genotype responded positively, indicating that individuals not directly affected by the disease can be mobilized to participate (50%).

The respondent's opinions were also directly sought; in response to the question "Did your knowledge of your genotype impact your involvement in SCD," responses are shown in Table 7.

*Table 7: **Perceived Effect of Genotype Knowledge on SCD Engagement***

Response	Frequency (n)	Percentage (%)
Strongly Agree	13	40.6%
Agree	9	28.1%
Neutral	2	6.3%
Disagree	6	18.8%
Strongly Disagree	1	3.1%
Total	31*	--

**One respondent did not answer this question.*

An overall sum of 68.7% believed they either agreed or strongly agreed that genotype information influences their involvement in SCD advocacy. These findings confirm the

underlying theory in the study that genotype information influences participation in advocacy for a substantial majority. On the contrary, 21.9% neither agree nor disagree that genotype information influences their involvement in advocacy, suggesting that personal genotype status may not always be a driving force for advocacy, other possible influences could include a person's profession, community affiliation, personal values, and family background.

3.7 Having a Personal Connection to SCD as a Predictor of Advocacy

Using cross-tabulation, it becomes clear that the strength of association between having a personal or family connection to SCD and participation in advocacy is greater than that for having knowledge of one's genotype alone.

*Table 8: **Personal SCD Connection vs. Advocacy Participation***

Personal SCD Connection	Advocated (n)	Did Not Advocate (n)	Advocacy Rate (%)
Yes	12	3	80.0%
No	6	8	42.9%
Not Sure	1	2	33.3%

Respondents who were personal affected or who have an affected family member, were more likely to advocate (80.0%) than respondents who are not personally affected (42.9%). This suggests that being personally familiar with the problem of SCD (regardless of whether it has been diagnosed genetically) is a stronger behavioral predictor of advocacy than knowledge of one's own genotype. Emotional familiarity with a situation (which personal knowledge of a condition is) may be key to bridging the gap between knowledge and action.

3.8 Personal Connection to the Cause Among the Non-Affected Genotypes

Among those respondents who did not have a disease-causing genotype (i.e. AA, AC, and AS), the survey asked whether or not the respondent felt connected to the cause of SCD. This data is presented in Table 9.

*Table 9: **Sense of Connection to SCD Cause (AA/AS Respondents)***

Level of Connection	Frequency (n)	Percentage (%)
Deeply connected and actively involved	12	41.4%
Connected but not actively involved	12	41.4%
Not sure	2	6.9%
Not strongly connected	2	6.9%
Prefer not to say	1	3.4%

Overall, 82.8% of AA/AS respondents indicated they are at least somewhat connected to the SCD cause, and 41.4% describe themselves as intensely or moderately committed. This is crucial-it questions the premise that the SCD advocacy effort will be predominantly executed by and within those who are directly touched by SCD, suggesting instead that there exists a vast number of empathetic allies who are available to be more involved if engaged.

3.9 Advocacy enablers

Respondents described which factors they believed would most motivate people to increase their support for SCD advocacy. This question was a multiple selection question and aggregated across the 32 total respondents.

*Table 10: **Advocacy Enablers (Ranked by Frequency)***

Enabler	Frequency (n)	% of Respondents
More education about SCD and its impact	20	62.5%
Easy ways to contribute (reposting, donating, volunteering)	14	43.8%
Involvement in school, workplace, or faith-based advocacy	13	40.6%
Opportunities to join community events or campaigns	12	37.5%
Seeing real-life stories of people living with SCD	11	34.4%
Knowing someone personally affected by SCD	9	28.1%

Clear evidence that advocacy makes a difference	7	21.9%
Understanding how my genotype is connected	6	18.8%
If I were invited directly to participate	5	15.6%
Collaboration with public figures or influencers	4	12.5%

The top three enablers of advocacy were: education (62.5%), easy mechanisms for contribution (43.8%), and institutional integration into schools/workplaces/faith communities (40.6%). Education as the most important enabler is consistent with broader public health research on behavior change communication; knowledge is the precursor to behavior. The demand for easy contribution mechanisms highlights friction reduction as a key aspect of campaign design for advocacy professionals. The low ranking of working with influencers (12.5%) suggests that grass-roots authenticity may be valued by respondents more than celebrity engagement.

3.10 Personal Narratives: Qualitative Themes

Thirteen participants (40.6%) supplied their personal narratives in the open-ended story box. Analysis of these narratives yielded four dominant themes:

- **Stigma and Social Marginalization**: A strong theme in narratives was labeling and exclusion by teachers, peers and healthcare professionals. One narrative detailed how teachers told a mother her parents were wasting money trying to help their sickle cell child. This represents a clear example of educational stigma.
- **Resilience and Identity Reclamation**: Many stories spoke of a process of turning away from the shame of their condition toward self-acceptance. Respondents framed SCD as a source of inner strength and resiliency, and not something to be seen as a death sentence.
- **Calls for Genotype Testing and Pre-marital Screening**: The importance of knowing one's genotype prior to marriage and other genetic decisions was reiterated throughout many of the narratives, often summarized by the statement, "Know your genotype before you say I do."
- **Advocacy as Responsibility**: Some participants (particularly healthcare professionals and warriors) defined advocacy as both a personal responsibility to help themselves and other carriers and as a systemic requirement for research, policy change, and community support infrastructure.

4. Discussion

This survey provides novel evidence about factors motivating SCD advocacy in Nigeria. We identified key observations warranting further discussion.

First, it is important to note that this study's observation of 100% genotype awareness contrasts with general population data. Many studies such as Akodu et al. (2016) have reported genotype awareness to be as low as 20-40% within communities in Nigeria. Self-selection bias in this survey due to respondents' willingness to take health-related surveys makes the results ungeneralizable to the whole population; nevertheless, they provide insight: awareness alone is insufficient to promote advocacy as 40% of these respondents who were aware had not undertaken any form of advocacy.

Second, the observed finding that personal connection is a stronger predictor of advocacy than genotype is programmatically significant. For instance, interventions aimed at increasing advocacy through increased testing may not be effective. Emotional connection building through stories, interaction with warriors and with others will more likely lead to sustained advocacy. Health Belief Model (Rosenstock, 1974) highlights susceptibility and severity of a condition as core motivators for health behavior protection, both of which likely apply to those with closer personal connections to SCD.

Third, the finding that AS carriers (34.4%) reported higher than average rates of advocacy (63.6%) are contrary to prevalent assumptions that carriers will not be motivated to advocate as they have no outward phenotypic expression. The reproductive implications associated with AS status (25% likelihood of SS birth with AS parents) may represent a strong motivation for carriers to engage in advocacy; this could be an important campaign opportunity if successfully addressed.

Fourth, education as the most commonly reported advocacy enabler (62.5%) emphasizes the centrality of health literacy to the advocacy pathway. However, as shown by the second and third enablers of easy contribution mechanisms and institutionalization, education alone is not sufficient to overcome structural obstacles that prevent advocacy, hence campaign designs must incorporate both.

Fifth, qualitative data provides much-needed human context to quantitative findings. It is compelling that in spite of the diversity within this group of survey participants, stigma, resilience, genotype testing and systemic advocacy emerge as common themes. These resonate strongly with those identified in broader SCD advocacy literature throughout Sub-Saharan Africa.

5. Conclusions and Recommendations

5.1 Conclusions

This survey found high genotype awareness, SCD knowledge, and advocacy participation within a sample of health-engaged Nigerian adults. We learned that having a personal connection to SCD as a predictor of advocacy behavior is greater than having a particular genotype. Most respondents believed genotype information drives advocacy, and many AA/AS individuals report a sense of commitment, suggesting that these individuals represent an unexploited group of advocates. Education as the most common enabler is an important piece of information for those seeking to reach potential advocates, as is their desire for easy contribution mechanisms and institutional integration.

5.2 Recommendations

- Based on this study, the following are recommendations for those planning and executing advocacy campaign in Nigeria:
- Use narrative-centred advocacy strategies. Narrative-centred campaigns that showcase the voices of AS carriers and warriors will be most effective at drawing audiences in.
- Reduce barriers to participation. In addition to informational, encourage the creation of accessible, simple pathways for those interested in helping (e.g., sharing social media posts, making small donations, local volunteering).
- Mainstream SCD education. Education within schools, workplaces and places of worship is key to expanding the reach of SCD information.
- Capitalize on the willingness of AS carriers to advocate. Support advocacy messaging aimed at AS carriers to address the risks of transmitting the disease and promote their role as allies.
- Promote widespread genotype testing. Given the current status in Nigeria, education around genotype testing as a preventive health behavior needs continued attention.
- Integrate anti-stigma interventions into all advocacy efforts. Stigma is a powerful impediment to SCD advocacy that will likely only diminish through direct efforts to dismantle its prevalence.
- Broaden and replicate this study. The findings are from a limited sample size, so expanded studies are necessary to gain insight into larger, diverse samples in Nigeria (e.g. Different regions, rural vs. Urban dwellers, varying socioeconomic levels, different ethnic groups, etc).

6. Limitations

Several limitations must be considered when interpreting this study. The sample size of 32 offers very limited statistical power and is unrepresentative. The most significant limitation of this survey is the pronounced selection bias. This survey, distributed online, asked participants to take part in SCD advocacy research, which inherently selects for individuals with a heightened interest and awareness in health, thus not representing the Nigerian population as a whole. Response rates cannot be definitively assessed given the online format and the likely presence of social desirability bias with questions of this nature.Finally, as a cross-sectional study, the direction of relationships between genotype and advocacy can not be determined and causal inferences cannot be drawn.

References

Akodu, S. O., Diaku-Akinwumi, I. N., & Njokanma, O. F. (2016). Age at diagnosis of sickle cell anaemia in Lagos, Nigeria. Paediatric Haematology and Oncology, 33(7-8), 430-436.

Anie, K. A., & Green, J. (2015). Psychological therapies for sickle cell disease and pain. Cochrane Database of Systematic Reviews, (5), CD001916.

Piel, F. B., Patil, A. P., Howes, R. E., Nyangiri, O. A., Gething, P. W., Dewi, M., Temperley, W. H., Williams, T. N., Weatherall, D. J., & Hay, S. I. (2013). Global epidemiology of sickle haemoglobin in neonates: A contemporary geostatistical model-based map and population estimates. The Lancet, 381(9861), 142-151.

Rosenstock, I. M. (1974). Historical origins of the Health Belief Model. Health Education Monographs, 2(4), 328-335.

World Health Organization. (2006). Sickle-cell anaemia: Report by the Secretariat. WHO Executive Board, 117th Session. EB117/34.

Appendix: Summary of Quantitative Findings

Table A1: Complete Frequency Summary

Survey Item	Key Finding
Know genotype	100% (32/32) -- Yes
Genotype distribution	AA: 43.8%, AS: 34.4%, SS: 15.6%, SC: 6.3%
Personal/family SCD connection	Yes: 46.9%, No: 43.8%, Not sure: 9.4%
SCD a major community issue	Yes: 50.0%, No: 31.3%, Not sure: 18.8%
SCD knowledge rating >= 4	71.9% (23/32)
Participated in SCD advocacy	Yes: 59.4% (19/32)
Genotype affects engagement (Agree/Strongly Agree)	68.7% (22/31)
AA/AS feel connected to cause	82.8% (24/29)
Open to follow-up	65.6% (21/32)
Top advocacy activity	Educating others about genotype and SCD
Top advocacy enabler	More education about SCD (62.5%)