ACQUAINT PUBLICATIONS
Journal of Community Medicine and Public Health Reports ISSN: 2692-9899
Technical Report
Volume 6 Issue 08

Strengthening Evidence Based Management Of Sickle Cell Disease In A Control Programme By Setting Up Registries, Screening Services And Strengthening The Specialized Clinics In Five Pilot Counties Of Western Kenya

Constance N Tenge[1,2*], Mabel N Nangami1[1,2], Bernard M Sorre[1,2], Frederick O Okinyi[2,3], Meshack W Liru [3,4], Eunice Owino[2], Maurice Shilabula[2]

[1]Moi University (M.U).

[2]Sickle Cell Federation of Kenya (SFK).

[3]University of Nairobi (U.O.N).

[4]Homabay County Hospital.

***Corresponding Author:** Constance N Tenge, Professor of Paediatrics at the Moi University, College of Health Sciences, School of Medicine, Department of Child Health and Paediatrics

Received date: 28 August 2025; **Accepted date:** 10 September 2025; **Published date:** 27 October 2025

Citation: Tenge CN, Nangami MN, Sorre BM, Okinyi FO, Liru MW, et al. (2025) Strengthening Evidence Based Management Of Sickle Cell Disease In A Control Programme By Setting Up Registries, Screening Services And Strengthening The Specialized Clinics In Five Pilot Counties Of Western Kenya. J Comm Med and Pub Health Rep 6(08): https://doi.org/10.38207/JCMPHR/2025/OCT06080159

Copyright: © 2025 Constance N Tenge. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

Abstract

Sickle Cell Disease (SCD) is a genetic or inherited blood disorder of the red blood cells. The inheritance is autosomal recessive, which means that those individuals that inherit the gene from one parent are carriers who generally lead normal lives without symptoms but have the potential to transmit the gene to their offspring, while those individuals who inherit the gene from both parents suffer a lifelong illness whose symptoms present as acute or chronic complications of anemia, vaso-occlusion, infections and organ damage.

The control of SCD is categorized by the World Health Organization (WHO) into Primary, Secondary and Tertiary interventional strategies which can be effective if carried out concurrently.

The overarching objective of this study was to assess the level of awareness of Health Care Providers (HCP) on SCD, to evaluate the existing health care services for SCD and to register the PLWSCD with the aim of using the findings to strengthen evidence-based management of SCD in a control programme through setting up registries, screening services and strengthening the specialized clinics.

The study team first obtained all the required ethical approvals from the relevant Institutional Research Boards (IRB) which included the IREC-MTRH/MU (Institutional Ethics and Research Committee-Moi Teaching and Referral Hospital and Moi University), NACOSTI (National Commission for Science, Technology and Innovation) and permission from the various counties in which the activities were carried out. The study team also prepared the power point presentations for the Continuous Medical Education (CME) sessions, the data collection tools or questionnaires (Registry forms and Key Informant Interviews) and the test questions. The study team also recruited and trained the Registry Administrators (RA) to collect the data. The team then discussed the study with the various County Health Management Teams (CHMT) and handed over copies of the concept note, ethical approvals, data collection tools together with the first edition of the Kenya SCD management guidelines. Thereafter, the team organized for the Continuous Medical Education (CME) sessions. The team carried out the activities according to the objectives, collected data, analyzed, gave feedback to the CHMTs and has written this Technical Report.

The study team assessed the level of knowledge on SCD of various cadres of staff (Doctors, Clinical Officers, Nursing officers, Public Health Officers, Nutritionists and etc.) in the 5 different counties. The HCPs were exposed initially to a Pre-test, a Continuous Medical Education (CME) session and then a Post-test. The average score of Pre-test done by 2118 HCPs was 4.6 (maximum 15) while the average score of the Post-test done by 2670 HCPs was 8.3 (maximum 15). The positive trends in improvement in knowledge call for further efforts in dissemination of the required information on SCD through various forums.

This study evaluated existing SCD care services in 76 health facilities out of which 67(88.2%) were public, 7(9.2%) were Faith-based while 2 (2.6%) were private. Majority of the facilities 43 (56.6%) were level 4 followed by 25(32.9%) which were level 3. The facilities which reported that they attend to PLWSCD were 50 (65.8%) but only 12(15.8%) indicated that they sometimes stock hydroxyurea which is the main medication required in the management of SCD. Most of the facilities lacked diagnostic and monitoring equipment as well as the medications required by PLWSCD. All the 76 (100%) facilities indicated that they are NHIF accredited, have pharmacy and laboratory departments together with both

skilled (medical) and unskilled(non-medical) staff. These findings call for the purchase and stocking of the basic medicines required by PLWSCD as well as the purchase and installation of the equipment and reagents required for screening, diagnosis and monitoring of cases of SCD.

This study registered a total of 2056 PLWSCD out which 1745(84.9%) of were aged less than 18 years and therefore dependent on their parents or guardians while only 23 (1.1%) were aged more than 45 years. Those who indicated that they knew of some relative(s) with SCD were 859(41.8%). Regarding the diagnostic work up, only 357(17.3%) had a confirmatory test (HB Electrophoresis/ HPLC) while majority 1500 (73.0%) had a screening test (sickling test) done. Most of the PLWSCD reported having had multiple hospital admissions and multiple blood transfusions. The families of PLWSCD who had ever enrolled in a medical cover were 941 (45.8%) with majority 730(77.6%) of them paying the premiums by direct remission in to the fund, however only 34.1% (702 out of 2056) had an active and beneficial medical cover with only 30.8% (633) PLWSCD being able to access and afford hydroxyurea. These findings call for establishment of SCD registries (PLWSCD, Haemoglobin Variants, Organizations that deal with SCD) and strengthening of specialized clinics by ensuring that medications, supplies, reagents and equipment are available, accessible and affordable so that the communities are able to receive the services required for the control of SCD. To make the services affordable, all families including those of PLWSCD should be encouraged, guided and supported to purchase a medical insurance cover. The health care leadership and other stakeholders need also to lobby for an, 'essential package' from the existing Health Insurance Fund for PLWSCD. As an appropriate way forward towards the realization of a SCD registries and Control Programme (SCDRCP), the study team has designed various tools to assist collect standardized information which can be analyzed and used for intervention projects.

- **Organizations that deal with SCD (Appendix I)**

The organizations that deal with SCD are expected to register, indicate the scope (care, advocacy, capacity building, etc.) of their activities and periodically provide reports of their work to the relevant authorities. The study team also recommends that appropriate standards of the activities are set and adhered to.

- **Encounter (Initial and Return) Forms (Appendix IV & V).**

These are to be used for the patients' files and retained in the clinics/ facilities.

The initial encounter forms are designed to provide data for the registry of PLWSCD and collect information on the demographics, family set up and whether the family has a medical insurance, whether it also identifies with a community health worker/promoter, mode of diagnosis of the SCD, medical treatment and name of facility.

The return encounter forms are designed to collect information on whether the client has an active medical insurance or not, intercurrent information (use of medications, hospital admissions, blood transfusions, interaction with Community Health Workers) since last visit and referral for specialized care.

- **Haemoglobin Variant Forms (Appendix III).**

These are to provide data for the registry of the type of haemoglobin different persons have. People are encouraged to screen and know the type of haemoglobin variant they have and there make informed choices about their spouses and offspring.

- **Sickle Cell Federation of Kenya (SFK) Membership Forms (Appendix II).**

The SFK membership forms seek to register any stakeholders (PLWSCD and their caretakers, Health Care Providers, any other individuals) that are interested in the welfare of PLWSCD within the jurisdiction of Kenya.

The SFK is an umbrella organization whose aim is to work closely with the Ministry of Health (MOH) and the County Health Management Teams (CHMT) to set the appropriate standards of CARE, EDUCATION and RESEARCH in SCD.

Another appropriate way forward is to have the **Ministry of Health** and **County Health Management Teams** to **take charge** of the activities and ensure that the **implementation of the WHO interventional strategies** is carried out **concurrently in an organized manner.**

Duration: (6 MONTHS) - NOVEMBER 2021 TO APRIL 2022.

Table Of Content

Abstract..... 1
1.0 INTRODUCTION..... 4
1.1 Objectives…..... 4
1.2 DESCRIPTION OF APPROACH..... 4
1.2.1 STUDY PROCEDURES..... 5
1.2.1.1 Phase I..... 5
1.2.1.2 Phase II..... 5
1.2.1.2 Phase III..... 5
2.0 METHODOLOGY AND RESULTS..... 5
2.1 OBJECTIVE ONE..... 5
Assessment of the Level of Awareness About Sickle Cell Disease (SCD) Among Health Care Provider (HCPS) 5
2.2 OBJECTIVE TWO..... 8
Evaluation of The Existing Health Care Services for SCD..... 8
2.3 OBJECTIVE THREE..... 11
Registration of Persons Living with Sickle Cell Disease (PLWSCD)..... 11
2.4 OBJECTIVE 4..... 18
Determination of The Haemoglobin Variants of Different Demographic Groups Including New Born..... 18
3.0 DISCUSSION..... 18
4.0 CONCLUSION AND RECOMMENDATION..... 20
4.1 Conclusion..... 20
4.2 Recommendations/ Call to action..... 20
Abbreviations And Acronyms..... 22
Appendix I - SCD Organizations Form..... 22
Appendix II - SFK Membership Form..... 24
Appendix III - Registry Form (Haemoglobin Variant)..... 26
HBV Screening Form…..... 27
HBV Cliints Copy..... 28
HBV Summary Sheet..... 29
Appendix IV - Initial Encounter Form.....30
Appendix V - Return Encounter Form.....32
SCD Clinic Summary..... 35
Appendix VI - Questionnaire for Evaluating Health Facilities..... 36
Appendix VII- Understanding SCD Pamphlet.....37
Appendix VIII -Test Questions and Explanations..... 38
Funder..... 49
Researchers..... 49
Acknowledgement..... 49
REFERENCES..... 50

1.0 Introduction

Sickle Cell Disease (SCD) affects millions of people throughout the world. **[1]** More than three quarters (75-85%) of the cases occur in Africa, it affects 3% of births with an estimate of 300,000 to 400,000 infants born with SCD annually. **[2, 3]** The carrier (Sickle Cell Trait) frequency ranges between 10% to 40% across equatorial Africa decreasing to 1% to 2% on the North African coast and less than 1% in South Africa. **[2]** The prevalence of SCD in the United States is approximately 1 in 5,000 mostly affecting Americans of Sub-Saharan descent. It is estimated that about 2.5 million Americans are heterozygous carriers and 90,000 are affected with the sickle cell disease In France, overall birth prevalence was found to be 1 in 2415 with about 8744 carriers. In the United Kingdom, one baby in every 2000 is born with SCD. In South Arabia, about 4.2% of the population carry the sickle cell trait and 0.26% have sickle cell disease. The prevalence of SCD in India ranges from 9.4% to 22.2%. **[4]**

In Kenya, most of the cases are found in Western, Nyanza, Coast, Nairobi and parts of Eastern regions or provinces. **[4, 5]** Aluoch J. R. et al in 1993 documented that more than 80% of patients with sickle cell anaemia were of Luo and Luhya origin with Sickle Cell Trait (SCT) rate of 28% among them while among the Kamba and Mijikenda, the SCT rate is about 35%. **[5]** Kuta E et al in 2016 documented the prevalence of SCD of 3.2% and SCT of 13.2% among newborns in Kisumu while Watenga et al in 2017 found the prevalence of SCT of 18.7 % among adolescents in Bungoma county, Kenya. **[6, 7]**

There is paucity of population level data in general regarding the burden of SCD and the sickle cell trait (SCT) in Kenya, East Africa and the African continent at large. **[1]** Based on model projections, it is estimated that in Kenya, almost 6,000 newborns (one in every 150 newborns) had sickle cell in 2010, and this could rise to over 10,000 (one in every 100 newborns) per year if appropriate control measures are not put in place**. [1]** The distribution reflects the fact that Sickle Cell Trait (HB AS) confers a survival advantage against malaria and that selection pressure due to malaria has resulted in high frequencies of the mutant gene especially in high malarial transmission areas. **[8]**

SCD is a hereditary blood disorder. It is inherited in an autosomal recessive fashion. Any person carrying the sickle cell gene can transmit it to his/her offspring. **[4, 7]** Two categories exist –

- Those who have inherited the gene from one parent and are referred to as carriers or have the Sickle Cell Trait (SCT). They generally lead normal lives, do not show signs of disease but are often unaware that they carry the gene. However, they have the potential to transmit the gene. **[4, 7]**
- Those who have inherited the gene from both parents and are referred to as having Sickle Cell Anaemia (SCA). They suffer lifelong signs of sickness, which include anaemia, occlusion of blood vessels, infections and damage to various organs. **[4, 7]**

A person who has normal haemoglobin is referred to as having Hb AA, while the one who is a carrier is referred to as having Hb AS and the one who has the disease is referred as having Hb SS. The likelihood that a pregnancy will result into an offspring with Sickle Cell Anaemia (Hb SS) is 25 percent if both parents are carriers (Hb AS & Hb AS)), is 50 percent if one parent is a carrier and the other one is a sickler (Hb AS & Hb SS) and 100 percent if both parents are sicklers (Hb SS & Hb SS). **[4, 7]**

It is therefore, advisable that those who carry the gene (Hb AS and Hb SS) get spouses who have the normal haemoglobin (Hb AA) so that their offspring can have either the normal haemoglobin (Hb AA) or the trait (Hb AS). **[4, 7]** We argue that if we provide information to the public, screen, test and counsel, we can prevent the birth of sicklers in Kenya and therefore reduce the burden**. [4, 6, 7]**

The interventional strategies for control of SCD are categorized into primary, secondary and tertiary by the World Health Organization (WHO). **[4, 6, 7]** The tertiary interventional strategy entails managing the complications as the patients present with the signs and symptoms. The secondary interventional strategy entails screening the newborns, identifying those with SCD, follow them up and provide prophylactic management. The primary interventional strategy entails preventing birth of sicklers by ensuring persons are aware of their carrier status, there is pre-conception genetic counselling and reproductive choices made. **[4, 6, 7]** In order to be effective, all these intervention strategies should be carried out concurrently in an organized manner and in a SCD Control Programme. That is the focus of our project.

1.1Objectives

1. To assess the level of awareness about Sickle Cell Disease (SCD) among the Health Care Providers.
2. To evaluate the existing Health Care services for SCD.
3. To register the persons living with Sickle Cell Disease (PLWSCD).
4. To determine the haemoglobin variants of different demographic groups including New Born.

1.2Description Of Approach

The first essential step towards addressing the burden is to create a harmonized SCD data base, identify the patients and profile them in a standard format so as to help plan for their comprehensive care.[(4)] Another step is to set up services which can provide the appropriate facilities: for determination of haemoglobin variants so that individuals can test and know their 'sickle cell status'; public health education on prevention especially pre-conception genetic counselling and reproductive choices. The other very important step is to have an organized way in which all the relevant stakeholders can provide their support in terms of guidelines and policies, technical and expert services, funds for drugs, equipment and personnel among

others. **[4]** In Kenya the prevalence of sickle cell trait (SCT or HB AS) and sickle cell disease (SCD or HB SS) is not well established, therefore, if the interventional strategies are implemented appropriately through collaborative efforts of all stakeholders, establishment of a national registry of the various haemoglobin variants as well as a Sickle Cell Disease Registry and Control Programme (SCDRCP) can be realized.

1.2.1 Study Procedures

1.2.1.1 Phase I

The researchers first prepared registry forms for PLWSCD as well as the Haemoglobin variants (Appendix III) and the questionnaire for evaluating the health facilities (Appendix VI) plus the relevant information about SCD together with the need for implementation of Sickle Cell Disease Registries and Control Programme (SCDRCP). The information prepared targeted different groups of people and different cadres of staff and was modified from time to time depending on the audience and situation.

The researchers also prepared the pre-test and post-test questionnaires together with the categories of the test questions and narratives that provide the answers (Appendix VIII).

The tools were developed from scratch and subjected to various stakeholders for comments and improvement. In collaboration with the Ministry of Health and other stakeholders, targeted messages in form of Brochures (Appendix VII) to provide basic information on SCD were also developed and distributed.

1.2.1.2 Phase II

The researchers then interacted with the members of the County Health Management Teams (CHMT) in each of the 5 counties and gave presentations on the burden of SCD, the genetics, the interventional strategies and what can be done to control it and thus requested for their support. They also handed over to the CHMTs copies of the concept note, data collection tools, IREC- MU&MTRH and NACOSTI ethical approvals for the study together with the first edition of the Kenyan Guidelines for Management of SCD.

1.2.1.3 Phase III

After the approval of the activities by the CHMTs, the researchers planned the dates of the Continuous Medical Education (CME) sessions. The researchers also requested for the company of a member of the CHMT in each county during the activities. The researchers worked hand in hand with the County Health Management teams in all the activities in order to achieve the objectives.

Data Management

Data entry was done in an Excel Data Collection Template. Subsequent to this, data cleaning and management ensued through the comparison of the unprocessed data entered in Excel against the tangible data gathered via conventional paper data collection instruments, specifically targeting instances flagged by the data quality checks implemented during the data processing phase. This methodical approach facilitated the identification and resolution of discrepancies.

Further to this, a comprehensive Excel workbook was programmed, designed to afford intricate data drill-down capabilities. The workbook encapsulated the refined data, presenting descriptive statistical outputs viewable from the overarching project level and allowing for a granular exploration of the data at the facility level. This hierarchical presentation served to enhance the analytical depth and interpretative potential of the aggregated data, ultimately contributing to a more nuanced comprehension of the research findings.

The qualitative data collected through field notes was thematically grouped based on the research objectives and was used to augment the quantitative data.

The analysed data is presented in tables, pie charts and bar charts.

Phase IV

Dissemination Of Information

Feedback of the study findings was given in June 2023 to the CHMTs and suggestions on way forward provided.

A copy of the Power Point Presentation on the study findings was also given to the CHMT of each county.

This technical report has been shared with the Moi University, the Sickle Cell Federation of Kenya (SFK), the Ministry of Health and the various County Governments.

Information from the research study has been retained by the local health institution and the County, Moi University and the Sickle Cell Federation (SFK) and in future may be included in a de-identified public use data base managed by the Ministry of Health in compliance with the appropriate Public-Access Policy.

Data obtained will be useful to guide policy formulation and decision making and will therefore be shared appropriately with the relevant stakeholders.

2.0 Methodology And Results

2.0 Objective One

Assessment Of The Level Of Awareness About Sickle Cell Disease (SCD) Among Health Care Provider (HCPS).

Methodology

The researchers prepared the pre-test and post test questions which covered different aspects of Sickle Cell Disease. These included the history and first description of SCD, the epidemiology, the genetics and mode of inheritance, the pathogenesis and clinical features, the

management with special reference to the World Health Organization (WHO) interventional strategies and the need for SCD registries and Control Programme (SCDRCP). There were 4 different sets of the questionnaires labelled Pre-test A, B, C, D and Post-test A, B, C, D. Each set had 15 Multiple Choice Questions (MCQs) items with 4 choices that included an option of DO NOT KNOW with one answer being correct. At the time of the CME, the Health Care Providers were first subjected to a given set of Pre-test questions, then a Continuous Medical Education (CME) session of about 45 minutes was given and thereafter a different set of questions testing the same information was given as a post-test. The questions were marked out of 15. The sum of the total marks of all the HCPs was obtained and divided by the number of HCPs to get the average per facility and County. Analysis of the performance was done qualitatively. The number and cadre of the participants were determined and analysed quantitatively.

Results

Table 1: Distribution of the Health Care Providers (HCPs) by cadre per county.

	TOTAL	%	BUNGOMA	BUSIA	KAKAMEGA	VIHIGA	TRANS-NZOIA
No of HCP							
Reached							
Consultants	43	1.6	10	3	11	14	5
MO	102	3.8	18	23	32	15	14
CO	401	15.0	84	98	92	65	62
NO	1000	37.5	246	196	315	114	129
Lab Techs	253	9.5	49	55	56	42	51
PHO	109	4.1	27	28	22	10	22
Nutritionist	81	3.0	25	17	13	11	15
Social worker	60	2.2	16	16	7	9	12
Counsellor	103	3.9	19	35	12	19	18
HRIO	112	4.2	20	24	30	22	16
Pharm Tech	110	4.1	21	20	38	14	17
Others	296	11.1	88	32	65	58	53
	2,670	100	623	547	693	393	414

A total of 2670 Health Care Providers were assessed in the 5 counties with 623 in Bungoma, 547 in Busia, 693 in Kakamega, 393 in Vihiga and 414 in Trans- Nzoia. The numbers and the different cadres of staff assessed are as indicated in **Table 1**.

Tables 2, 3, 4, 5 and 6 show the average performance of the Health Care Providers in Bungoma, Busia, Kakamega, Vihiga and Trans-Nzoia respectively in the Pre-test and Post- tests.

Table 2: The pre-test and post-test performance of HCPs in Bungoma County

	Bungoma CRH	Bokoli	Kimalewa	Bumula	Lugulu Mission	Kamaeti	Chwele	Malakisi	Naitiri	Webuye	Cheptais	Mt. Elgon	Ndalu	Sirisia	Kimilili	TOTAL
Pretest																
Number	40	33	23	19	15	14	46	28	17	53	53	27	23	66	34	491
Marks	285	133	65	75	87	63	228	141	80	342	156	126	79	261	178	2299
Average	7.1	4.0	2.8	3.9	5.8	4.5	4.9	5.0	4.7	6.4	2.9	4.6	3.4	3.9	5.2	4.7
Posttest																
Number	46	44	32	26	21	19	55	42	27	57	55	37	32	74	56	623
Marks	454	285	165	208	187	142	318	267	193	540	341	211	256	584	459	4610
Average	9.9	6.5	5.2	8.0	8.9	7.5	5.8	6.4	7.2	9.5	6.2	5.7	8.0	7.9	8.2	7.4

Table 3: The pre-test and post-test performance of HCPs in Busia County.

	Busia CRH	West S cottage	Moding	Nambale	Nasewa	Alupe	Khunyangu	Kocholya	Butula	Nangina	Sio Port	Budalangi	Matayos	Angurai	Port Victoria	Changara	Mukhobola	Lukolis	Amukura	TOTAL
Pretest																				
Number.	32	11	10	30	11	40	42	38	15	27	13	10	19	15	30	17	14	15	28	417
Marks	219	61	50	181	51	193	237	225	68	149	73	44	122	67	148	68	62	71	147	2236
Average	6.8	5.5	5.0	6.0	4.6	4.8	5.6	5.9	4.5	5.5	5.6	4.4	6.4	4.5	4.9	4.0	4.4	4.7	5.2	5.3
Posttest																				
Number	40	13	13	35	16	55	54	49	15	47	17	10	35	17	37	24	15	22	33	547
Marks	437	103	101	295	125	431	509	404	113	386	175	93	274	139	300	163	147	202	255	4652
Average	10.9	7.9	7.8	8.4	7.8	7.8	9.4	8.2	7.5	8.2	10.3	9.3	7.8	8.2	8.1	6.8	9.8	9.2	7.7	8.5

Table 4: The pre-test and post-test performance of HCPs in Kakamega County.

	Kakamega CRH	Mukumu MH	Butere	Manyala	Navakholo	Makunga	Malava	Lumakanda	Mautuma	Matunda	Likuyani	St. Mary's Mumias	Matungu	Iguhu	Shibwe	Khwisero	TOTAL
Pretest																	
Total No.	47	72	25	22	38	26	42	43	40	35	38	38	36	25	32	26	585
Total Marks	216	340	126	101	156	112	206	181	124	137	185	190	148	115	141	96	2574
Averages	4.6	4.7	5.0	4.6	4.1	4.3	4.9	4.2	3.1	3.9	4.8	5.0	4.1	4.6	4.4	3.7	4.4
Posttest.																	
Total No.	61	98	31	22	48	29	46	50	46	36	43	47	41	30	37	28	693
Total Marks	560	872	338	200	422	278	451	460	341	288	366	526	344	279	337	96	6158
Averages	9.1	8.9	10.9	9.1	8.8	9.6	9.8	9.2	7.4	8.0	8.5	11.2	8.4	9.3	9.1	8.7	8.9

Table 5: The pre-test and post-test performance of HCPs in Vihiga County.

	VihigaCRH	Emusire	Bugina	Hamisi	Kaimosi	Ebusiratsi	Sabatia	Coptic	Mbale Rural	Emuhaya	Ipali	TOTAL
Pretest												
Number.	51	16	16	32	15	20	42	29	33	19	20	293
Marks	367	116	74	127	84	74	242	141	159	101	106	1591
Average	7.2	7.3	4.6	4.0	5.6	3.7	5.8	4.9	4.8	5.3	5.3	5.4
Posttest												
Number.	90	25	18	47	24	22	48	35	38	24	22	393
Marks	820	243	167	387	192	185	462	316	383	242	169	3566
Average	9.1	9.7	9.3	8.2	8.0	8.4	9.6	9.0	10.1	10.1	7.7	9.1

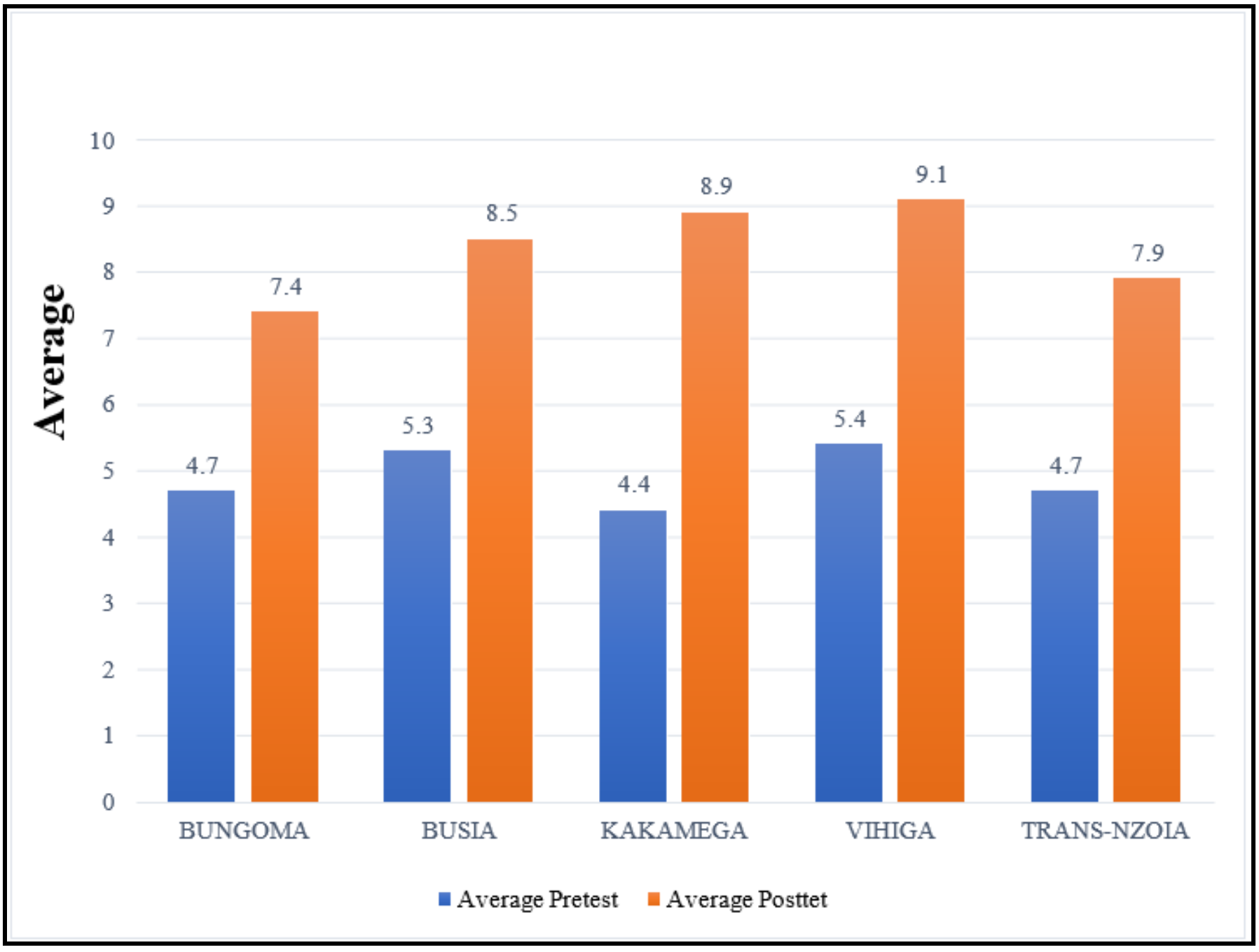
Table 6: The pre-test and post- test performance of HCPs in Trans-Nzoia County

	Kitale CRH	Lukhome	Saboti	Matunda	Gitwamba	Andersen	Kwanza	Bikeke	Kiminini	Kaplamai	Cherangany	Kapsara	Endebess	Kobos	Nzoia	TOTAL
Pretest																
Number	41	14	25	18	16	28	24	20	15	21	32	17	35	10	16	332
Marks	281	60	117	111	70	145	64	62	84	58	162	79	139	66	72	1570
Average	6.9	4.3	4.7	6.5	4.4	5.2	2.7	3.1	5.6	2.8	5.1	4.7	4	6.6	4.5	4.7
Posttest																
Number	48	17	26	25	27	31	26	33	19	32	33	27	39	12	19	414
Marks	469	145	247	169	166	247	236	246	154	204	273	178	287	91	146	3258
Average	9.8	8.5	9.5	6.8	6.2	8.0	9.1	7.5	8.1	6.4	8.3	6.6	7.4	7.6	7.8	7.9

Table 7: Summary of the pre-test and post-test performance of the HCPs in the 5 Counties.

COUNTY	PRE-TEST			POST-TEST		
	NO.	MARKS	AVERAGE	NO.	MARKS	AVERAGE
BUNGOMA	491	2306	4.7	623	4610	7.4
BUSIA	417	2236	5.3	547	4652	8.5
KAKAMEGA	585	2574	4.4	693	6158	8.9
VIHIGA	293	1591	5.4	393	3566	9.1
TRANS-NZOIA	332	1570	4.7	414	3258	7.9
TOTAL	2118	10277	4.9	2670	22244	8.3

Figure 1: Average score in the Pre-tests and Post-tests in each of the five counties.



Narrative (Objective one)

The average knowledge score on Sickle Cell Disease of the Health Care Providers was initially low with the HCPs scoring about one third (4.9 out of 15) of the total marks in the pre-test. Trends in improvement in knowledge were observed as evidenced in the post-test where the average mark improved to over half (8.3 out of 15) of the total marks.

Recommendation

1. Need to prepare Information, Education and Communication (IEC) materials with specific messages for dissemination.
2. Need to organize for more Continuous Medical Education (CME) sessions in order to reach more HCPs.

2.2Objective Two

Evaluation Of The Existing Health Care Services For SCD.

Methodology

An interviewer administered questionnaire (Appendix II) was filled by the researchers when they visited each facility. The facility in charge available at the time of the visit was asked as the Key Informant to provide the required information. The information collected included the name, level and type (public, faith based or private) of facility, whether the facility is NHIF accredited or not, whether it has pharmacy and laboratory departments, whether it attends to SCD clients, whether it stocks the specific medications (hydroxyurea, folate, Pen V, paludrine) for SCD and suggestions on what can be done to improve care services.

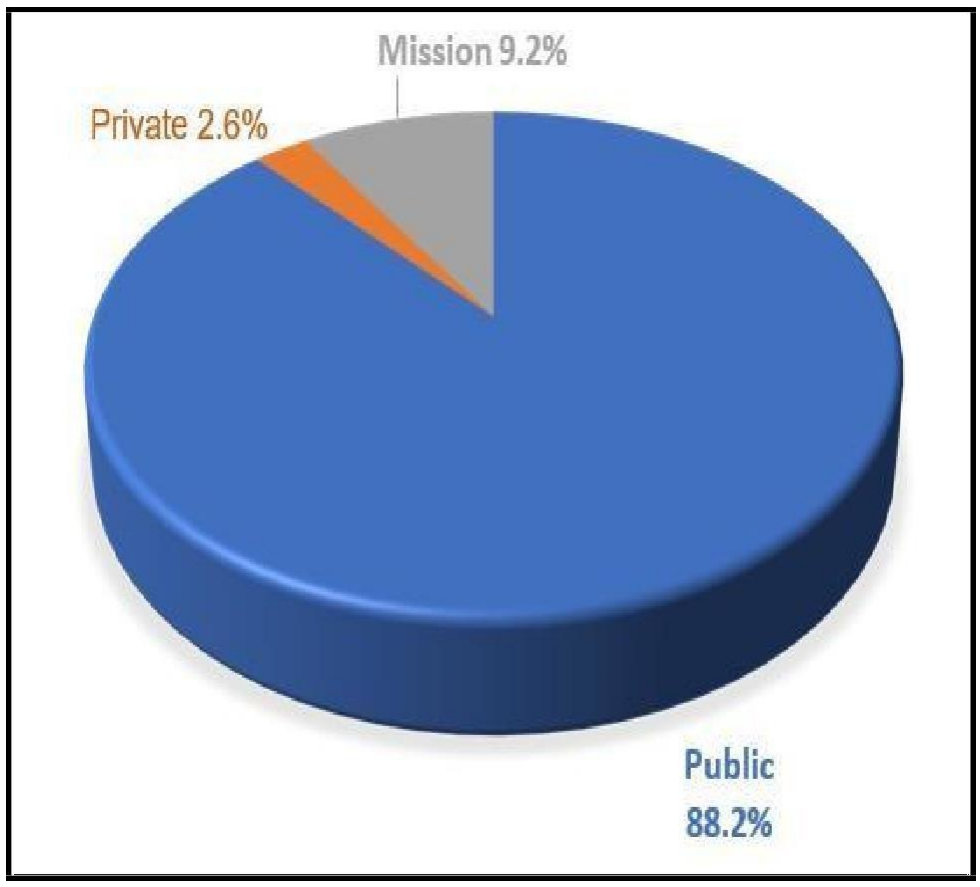
Results

Table 8: Names of the health facilities evaluated in each of the 5 counties

COUNTY	Health Facility Evaluated	Total
BUNGOMA	Bungoma CRH, Ndalu SCH, Kimalewa HC, Kameti HC, Cheptais SCH, Chwele SCH, Kimilili SCH, Lugulu Mission Hosp, Sirisia SCH, Malakisi SCH, Webuye SCH, Bumula SCH, Bokoli SCH, Naitiri SCH, Mt. Elgon SCH.	**15**
BUSIA	Busia CRH, Moding HC, West Side Cottage, Nasewa HC, Khunyangu SCH, Budalangi HC, Sio Port SCH, Lukolis HC, Amukura SCH, Matayos SCH, Alupe SCRH, Port Victoria SCH, Changara Dispensary, Mukhobola SCH, Holy Family Mission Hospital Nangina, Butula Mission HC, Ang'urai HC, Teso North SCH (Kocholia), Nambale SCH.	**19**
KAKAMEGA	Kakamega County General Hospital, Makunga SCH, Shinyalu SCH, Iguhu CH, Mautuma SCH, Shibwe SCH, Matunda SCH, Khwisero HC, Manyala SCH, Likuyani SCH, Navakholo SCH, Matungu SCH, Malava CH, ST. Mary's Mission Hosp Mumias, Butere CH, Lumakanda HC.	**16**
VIHIGA	Vihiga County Referral Hospital, Emuhaya SCH, Ebusiratsi SCH, Emusire HC, Bugina Model HC, Hamisi Sub-County Hospital, Jumuia Kaimosi Hosp, Ipali HC, Coptic Hospital, Mbale Rural Health Training Centre, Sabatia SHC.	**11**
TRANS- NZOIA	Kitale County Referral Hospital, Kwanza SCH Bikeke HC, Gitwamba HC, Matunda SCH, Saboti SCH, Lukhome HC, Kiminini HC, Kitale CRH, Kaplamai HC, Andersen Medical Centre, Kobos Heath Centre, Endebess Subcounty Hospital, Kapsara Subcounty Hospital, Cherangany Subcounty Hospital, Nzoia HC	**15**
TOTAL		**76**

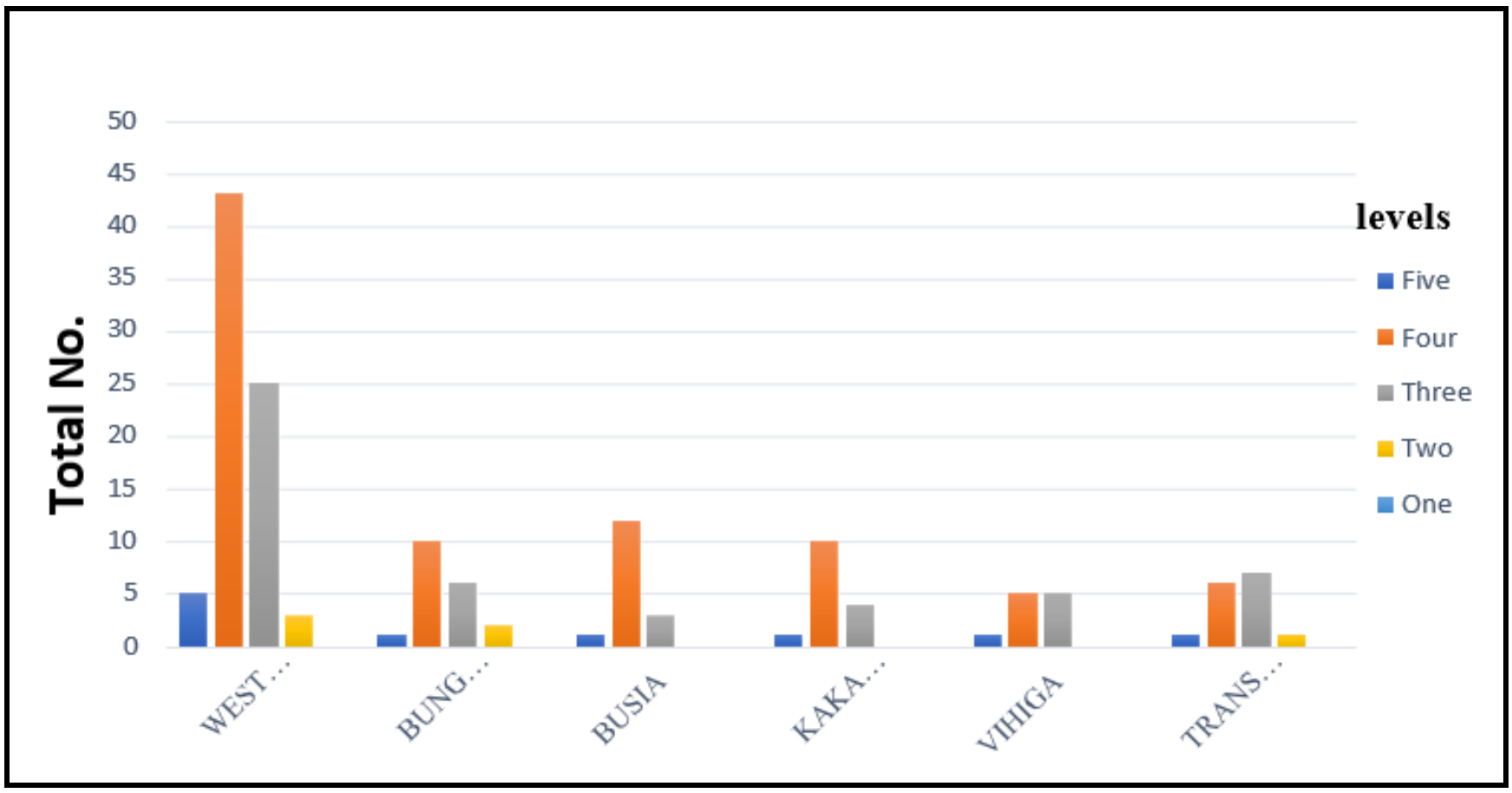
A total of 76 facilities in the 5 counties were evaluated as shown in **Table 8**. (Bungoma-15, Busia-19, Kakamega – 16, Vihiga-11, Trans-Nzoia-15).

Figure 2: Category of Health Facilities evaluated



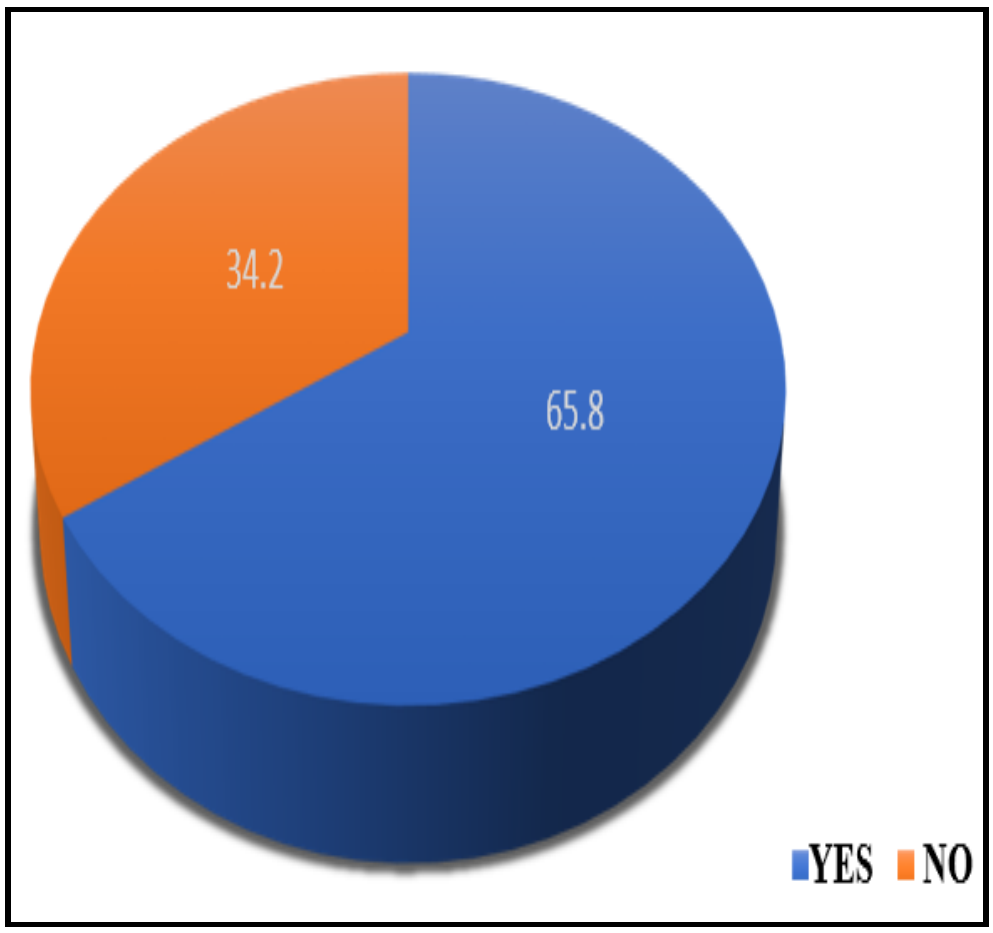
The public facilities were 67(88.2%), Faith based/ Mission were 7(9.2%) while private were 2(2.6%) as shown in **Figure 2**.

Figure 3: Level of Health Facilities evaluated in each of the 5 counties.



The level 5 facilities were 5(6.6%), level 4 was 43 (56.6%), level 3 were 25 (32.9%) and level 2 were 3 (3.9%) as shown in **Figure 3**.

Figure 4: Facilities that attend to SCD Clients



The facilities which attend to SCD clients were 50 (65.8%) as shown in **Figure 4**.

All the facilities were NHIF accredited, had pharmacy and laboratory departments and had skilled medical staff and non-medical staff (security, hospitality and grounds people).

Table 9: Facilities able to stock Medications and Vaccines for SCD

	WESTERN	BUNGOMA	BUSIA	KAKAMEGA	VIHIGA	TRANS-NZOIA
	No.% 76	No. %b15	No. % 19	No. % 16	No.% 11	No. % 15
MEDICATIONS						
FOLATE						
YES	56 73.7	80.0	57.9	81.3	81.8	11 73.3
NO	20 26.3	20.0	42.1	18.7	18.2	4 26.7
PEN V						
YES	16 21.0	20.0	26.3	18.7	27.3	2 13.3
NO	60 78.9	80.0	73.7	81.3	72.7	13 86.7
PALUDRINE						
YES	11 14.5	13.3	15.8	18.7	18.2	1 6.7
NO	65 85.5	86.7	84.2	81.3	81.8	14 93.3
HYDROXYUREA						
YES	12 15.8	13.3	15.8	18.7	27.3	1 6.7
NO	64 84.2	86.7	84.2	81.3	72.7	14 93.3
VACCINES						
PNEUMOCOCCAL						
YES	31 40.8	33.3	52.6	31.3	45.5	6 40.0
NO	45 59.2	66.7	47.4	68.7	54.5	9 60.0
MENINGOCOCCAL						
YES	4 5.3	13.3	10.5	0.0	0.0	0 0.0
NO	72 94.7	86.7	89.5	100.0	100.0	15 100.0

Narrative (Objective Two)

- Majority of the health facilities evaluated were public (67 ,88.2%) with most (68 ,89.5%) of them being level 3 and 4.
- All the facilities are NHIF accredited, have both laboratory and pharmacy departments and have skilled (medical staff) and support (non-medical) staff.
- Majority (50, 65.8%) of the facilities attend to SCD clients but only a few (12, 15.8%) could occasionally stock the main medication (Hydroxyurea) required by the PLWSCD and majority of the facilities cited challenges in getting reagents and equipment required for screening, diagnosis and monitoring of SCD.

Recommendations

i. There is need to capacitate the laboratories with reagents and purchase at least one equipment for confirmatory (HPLC or HB Electrophoresis) test for each county.
ii. Stock the pharmacies with the basic medications (Hydroxyurea, Pen V, Folate and analgesics) required by PLWSCD. Consider preparation or purchase of the appropriate formulations (Dispersible tablets and syrups) for children.
iii. Consider setting up revolving fund (Laboratory and Pharmacy) services.
iv. Request for an 'essential package' from the medical insurance cover for SCD care services.

2.3 Objective Three

Registration Of Persons Living With Sickle Cell Disease (PLWSCD).

Methodology

The researchers prepared interviewer administered questionnaires which were used to collect the data required for the registry of PLWSCD. The data that was collected included the demographics (Gender, Age, Residence, and Occupation), family (Socio- Economic status of parents), genetics (family history of SCD), possession of a medical insurance cover and its mode of payment, mode of diagnosis, hospital admissions, blood transfusions and ability to access and afford the medications required by PLWSCD. The researchers engaged Registry Administrators (RA) who were trained to collect the information. The registration was done either at the facilities where patients go for clinics or at the facilities where and when the researchers gave the CMEs.

Table 10: Number of PLWSCD registered per subcounty in each of the 5 counties

BUNGOMA SUBCOUNTIES									
Bumula	Kanduyi	Sirisia	Kabuchai	Kimilili	Tongaren	Webuye East	Webuye West	Mt. Elgon	**TOTAL**
79	158	48	99	49	38	28	68	39	**606**

BUSIA SUBCOUNTIES							
Teso North	Teso South	Nambale	Matayos	Butula	Samia	Bunyala	**TOTAL**
95	148	32	80	46	97	69	**567**

KAKAMEGA SUBCOUNTIES												
Butere	Matungu	Mumias East	Mumias West	Ikolomani	Khwisero	Lurambi	Shinyalu	Navakholo	Malava	Lugari	Likuyani	**TOTAL**
77	81	46	11	12	17	41	7	72	74	19	37	**494**

VIHIGA SUBCOUNTIES					
Vihiga	Sabatia	Hamisi	Emuhaya	Luanda	**TOTAL**
29	25	24	11	20	**109**

TRANS-NZOIA SUBCOUNTIES.					
Cherengany	Endebes	Kwanza	Kiminini	Saboti	**TOTAL**
29	32	44	125	50	**280**

Table 11: Demographic characteristics of PLWSCD

	WESTERN 2056		BUNGOMA 606		BUSIA 567		KAKAMEGA 494		VIHIGA 109		TRANS-NZOIA 280	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
No. of PLWSCD (2056)												
Male	972	47.3	279	46.0	278	49.0	216	43.7	59	54.1	140	50.0
Female	1084	52.7	327	54.0	289	51.0	278	56.3	50	45.9	140	50.0
Referrals (2056)												
NO	1826	88.8	572	94.4	550	97.0	422	85.4	105	96.3	177	63.2
YES	230	11.2	34	5.6	17	3.0	72	14.6	4	3.7	103	36.8
Age Distribution (2056)												
< 1 year	264	12.8	91	15.1	63	11.1	69	14.0	19	17.4	22	7.8
1 to < 5 yrs.	552	26.8	219	36.1	119	21.0	121	24.4	27	24.8	66	23.6
5 to < 18 yrs.	929	45.2	239	39.4	279	49.2	235	47.6	45	41.4	131	46.8
18 to < 25	143	7.0	28	4.6	40	7.1	35	7.1	6	5.5	34	12.1
25 to 45 yrs.	145	7.1	28	4.6	61	10.7	30	6.1	9	8.3	17	6.1
>45 yrs.	23	1.1	1	0.2	5	0.9	4	0.8	3	2.6	10	3.6
< 18 yrs.	1745	84.9	549	90.6	461	81.3	425	86.0	91	83.5	219	78.2
>=18 yrs.	311	15.1	57	9.4	106	18.7	69	14.0	18	6.5	61	21.8
Patient Occupation (2056)												
Child	776	37.7	373	61.5	167	29.5	104	21.1	85	78.3	47	16.8
Student	856	41.7	121	20.0	305	53.7	233	47.1	15	13.8	182	65.0
Unemployed	395	19.2	109	18.0	81	14.3	149	30.2	8	7.3	48	17.1
Employed (Informal)	20	1.0	3	0.5	10	1.8	4	0.8	0	0.0	3	1.1
Employed (Formal)	9	0.4	0	0.0	4	0.7	4	0.8	1	0.9	0	0.0

Figure 5: Age distribution of PLWSCD

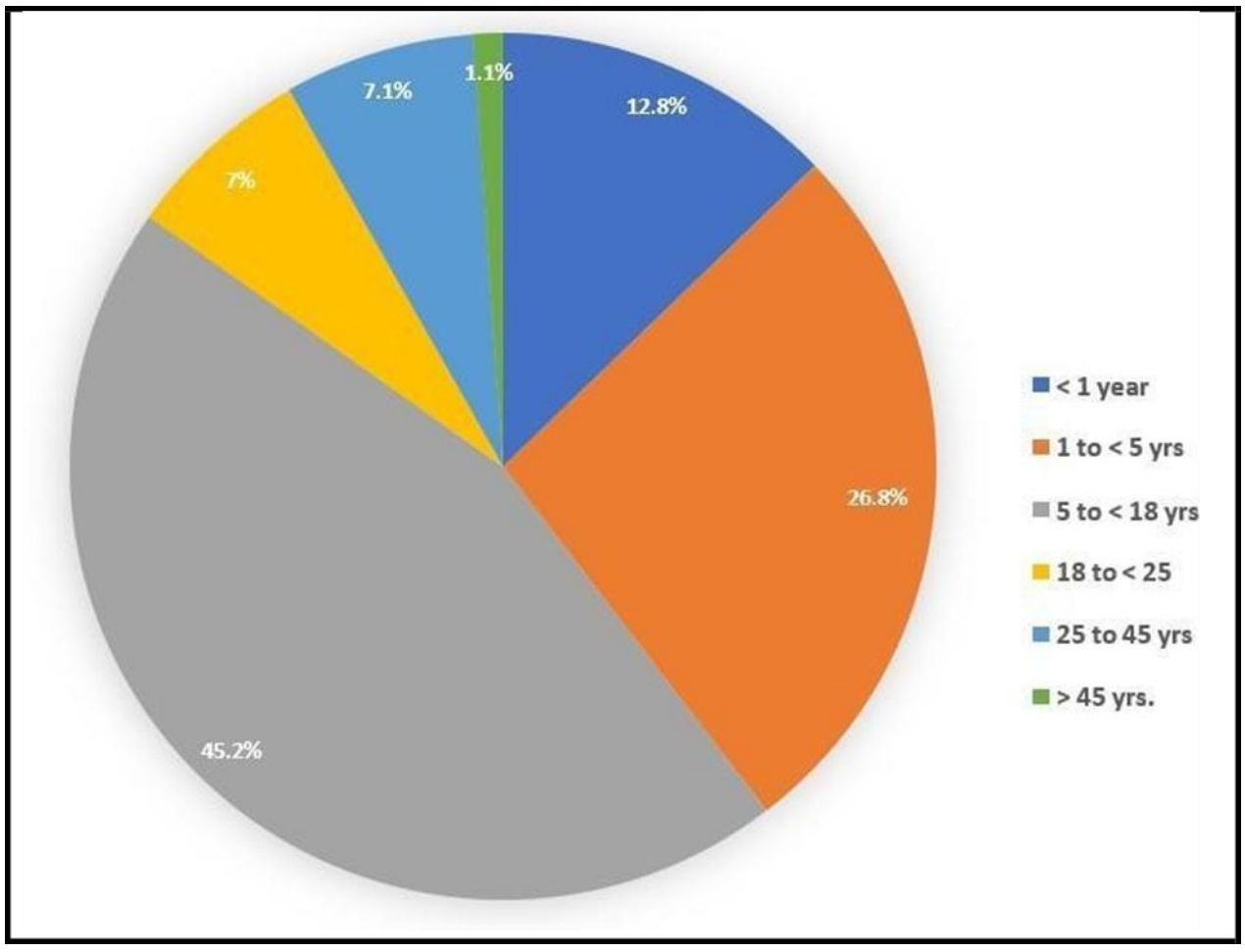


Table 12: Socio-economic status of parents of the PLWSCD

	WESTERN 2056		BUNGOMA 606		BUSIA 567		KAKAMEGA 494		VIHIGA 109		TRANSZOIA 280	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
MOTHER (2056)												
Alive	1985	96.4	597	98.5	544	96.0	490	99.2	105	96.3	249	88.9
Dead	71	3.6	9	1.5	23	4.0	4	0.8	4	3.7	31	11.1
Education												
None	670	32.6	116	19.1	249	44.0	169	34.2	29	26.6	107	38.2
Primary	689	33.5	195	32.2	193	34.0	175	35.4	35	32.1	91	32.5
Secondary	457	22.2	185	30.5	87	15.3	96	19.4	30	27.5	59	21.1
Tertiary	240	11.7	110	18.2	38	6.7	54	11.0	15	13.8	23	8.2
Employment (2056)												
YES	627	30.5	190	31.4	174	30.7	179	36.2	23	21.1	61	21.8
NO	1358	66.0	407	67.1	370	65.3	311	63.0	82	75.2	188	67.1
N/A(DEAD)	71	3.5	9	1.5	23	4.0	4	0.8	4	3.7	31	11.1
Marital status												
Married	1626	79.1	513	84.7	407	71.8	399	80.8	85	78.0	222	79.3
Not Married	430	20.9	93	15.3	160	28.2	95	19.2	24	22.0	58	20.7
FATHER (2056)												
Alive	1591	77.4	529	87.3	440	77.6	323	65.4	83	76.1	216	77.2
Dead	154	7.5	26	4.3	44	7.8	29	5.9	9	8.3	46	16.4
Unknown	311	15.1	51	8.4	83	14.6	142	28.7	17	15.6	18	6.4
Education												
None	576	28.0	143	23.6	211	37.2	107	21.7	24	22.0	91	32.5
Primary	453	22.0	115	19.0	139	24.5	96	19.4	17	15.6	86	30.7
Secondary	440	21.4	169	27.9	95	16.8	85	17.2	29	26.6	62	22.2
Tertiary	276	13.4	128	21.1	39	6.9	64	13.0	22	20.2	23	8.2
Unknown	311	15.2	51	8.4	83	14.6	142	28.7	17	15.6	18	6.4
Employment												
YES	1438	69.9	505	83.3	367	64.7	196	59.9	54	49.5	216	77.1
NO	618	30.1	101	16.7	200	35.3	198	40.1	55	50.5	64	22.9
Father Marital status												
Married	1626	79.1	513	84.7	407	71.8	399	80.8	85	78.0	222	79.3
Not Married	430	20.9	93	15.3	160	28.2	95	19.2	24	22.0	58	20.7

Table 13: History of SCD in the family

	WESTERN 2056		BUNGOMA 606		BUSIA 567		KAKAMEGA 494		VIHIGA 109		TRANS-NZOIA 280	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Relative Diagnosed with SCD												
Do not Know	92	4.5	10	1.7	26	4.6	9	1.8	10	9.2	37	13.2
NO	1105	53.7	354	58.4	294	1.9	284	57.5	64	58.7	109	38.9
YES	859	41.8	242	39.9	247	3.5	201	46.7	35	32.1	134	47.9
No. of Relatives (859)												
< 5	730	85.0	208	85.9	185	74.9	181	90.0	33	94.2	123	91.8
5-9	31	3.6	8	3.3	6	2.4	9	4.5	1	2.9	7	5.2
10+	17	2.0	6	2.5	7	2.8	0	0	0	0	4	3.0
Do not Know	81	9.4	20	8.3	49	19.9	11	5.5	1	2.9	0	0.0

Table 14: Status of medical insurance cover of families of PLWSCD

	WESTERN 2056		BUNGOMA 606		BUSIA 567		KAKAMEGA 494		VIHIGA 109		TRANS-NZOIA 280	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
MEDICAL COVER												
Ever enrolled (2056)												
NO	1115	54.2	330	54.5	299	52.7	241	48.8	57	52.3	188	67.1
YES	941	45.8	276	45.5	268	47.3	253	51.2	52	47.7	92	32.9
Medical cover (941)												
Not Active	239	25.4	53	19.2	91	34.0	52	20.6	13	25.0	30	32.6
Active	702	74.6	223	80.8	177	66.0	201	79.4	39	75.0	62	67.4
Cover SCD (2056)												
Do not Know	480	23.3	191	31.5	100	17.6	130	26.3	26	23.9	33	11.8
Yes	222	10.8	32	5.3	77	13.6	71	14.4	13	11.9	29	10.4
No	1354	65.9	383	63.2	390	68.8	293	59.3	70	64.2	218	77.8
Active &Beneficial (2056)												
YES	702	34.1	223	36.8	177	31.2	201	40.7	39	35.8	62	22.1
NO	1354	65.9	383	63.2	390	68.8	293	59.3	70	64.2	218	77.9
Mode Of Enrolment (941)												
Automatic	211	22.4	76	27.5	38	14.2	44	17.4	13	25.0	40	43.5
Direct Remission	730	77.6	200	72.5	230	85.8	209	82.6	39	75.0	52	56.5

Figure 6: Proportion of PLWSCD with Active and Beneficial Medical Cover

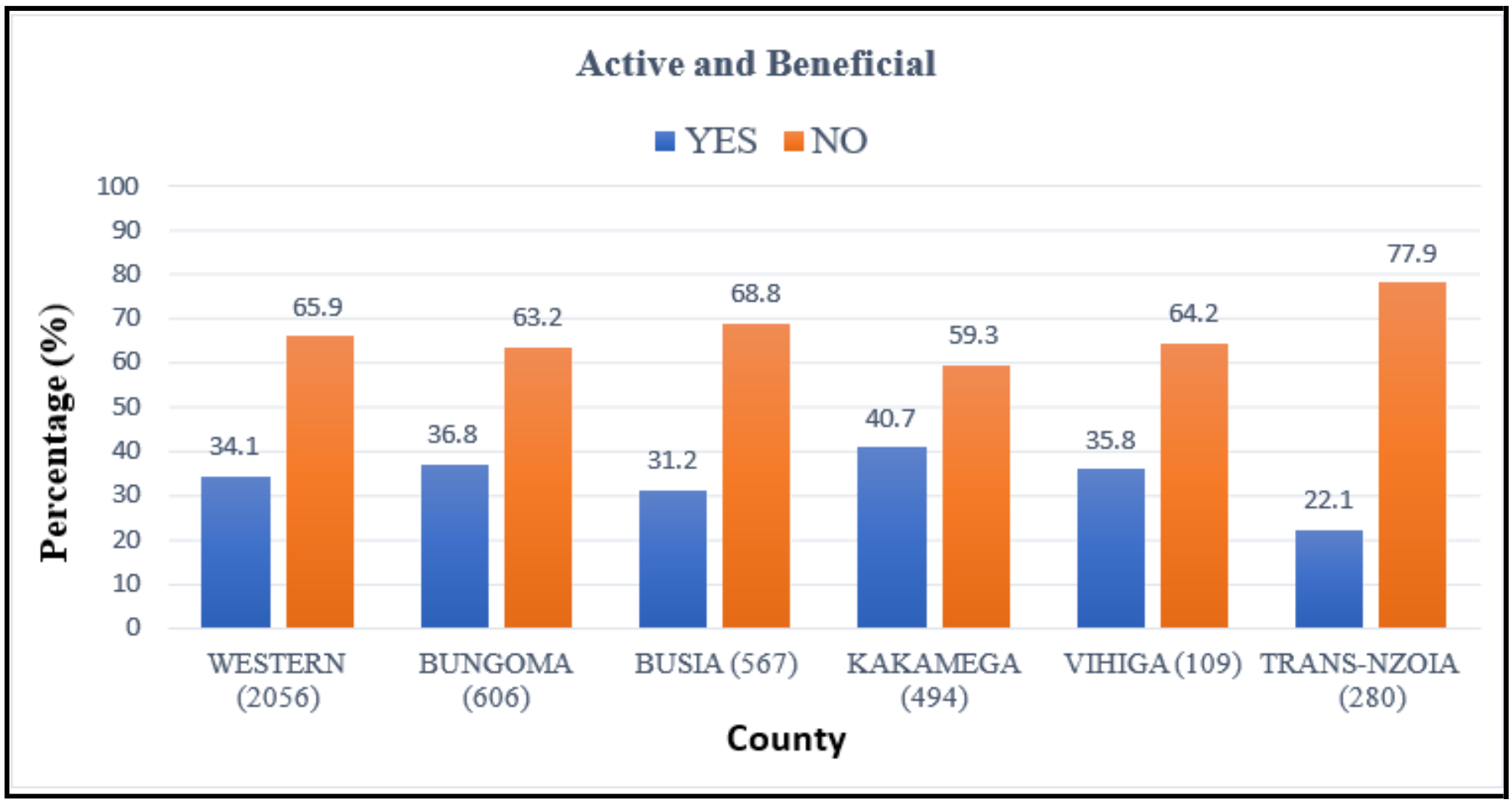


Figure 7: Mode of payment of the premiums for the medical insurance cover.

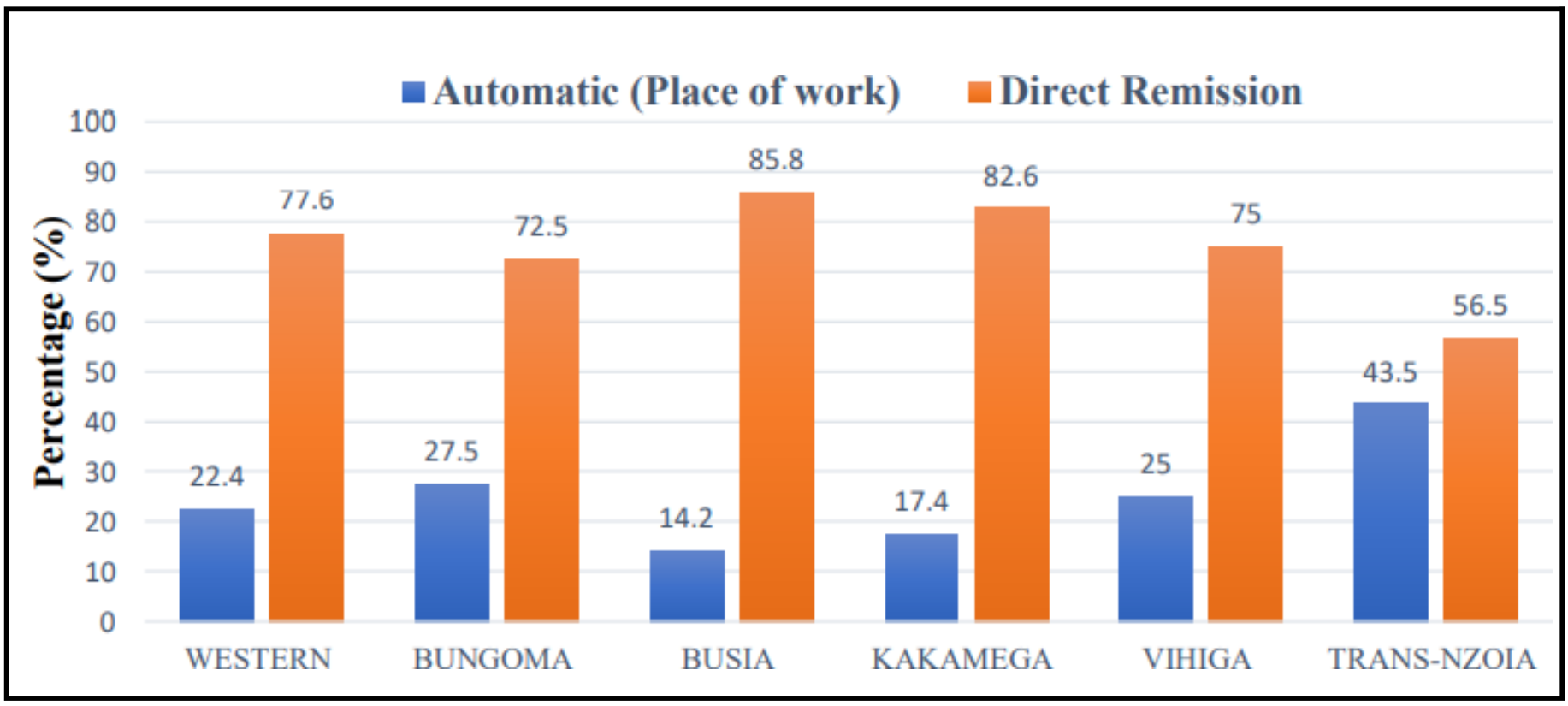


Table 15: Mode of diagnosis of SCD

	WESTERN 2056		BUNGOMA 606		BUSIA 567		KAKAMEGA 494		VIHIGA 109		TRANS-NZOIA 280	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Mode of Diagnosis of SCD (2056) **Clinically only**	199	9.7	52	8.6	28	4.9	50	10.1	7	6.4	62	22.1
Screening Test (Sickling Test)	1500	73.0	373	61.5	489	86.3	417	84.4	60	55.1	161	57.5
Confirmatory Test (HPLC/HB Ele)	357	17.3	181	29.9	50	8.8	27	5.5	42	38.5	57	20.4

Figure 8: Proportion of types of tests used for diagnosis of SCD.

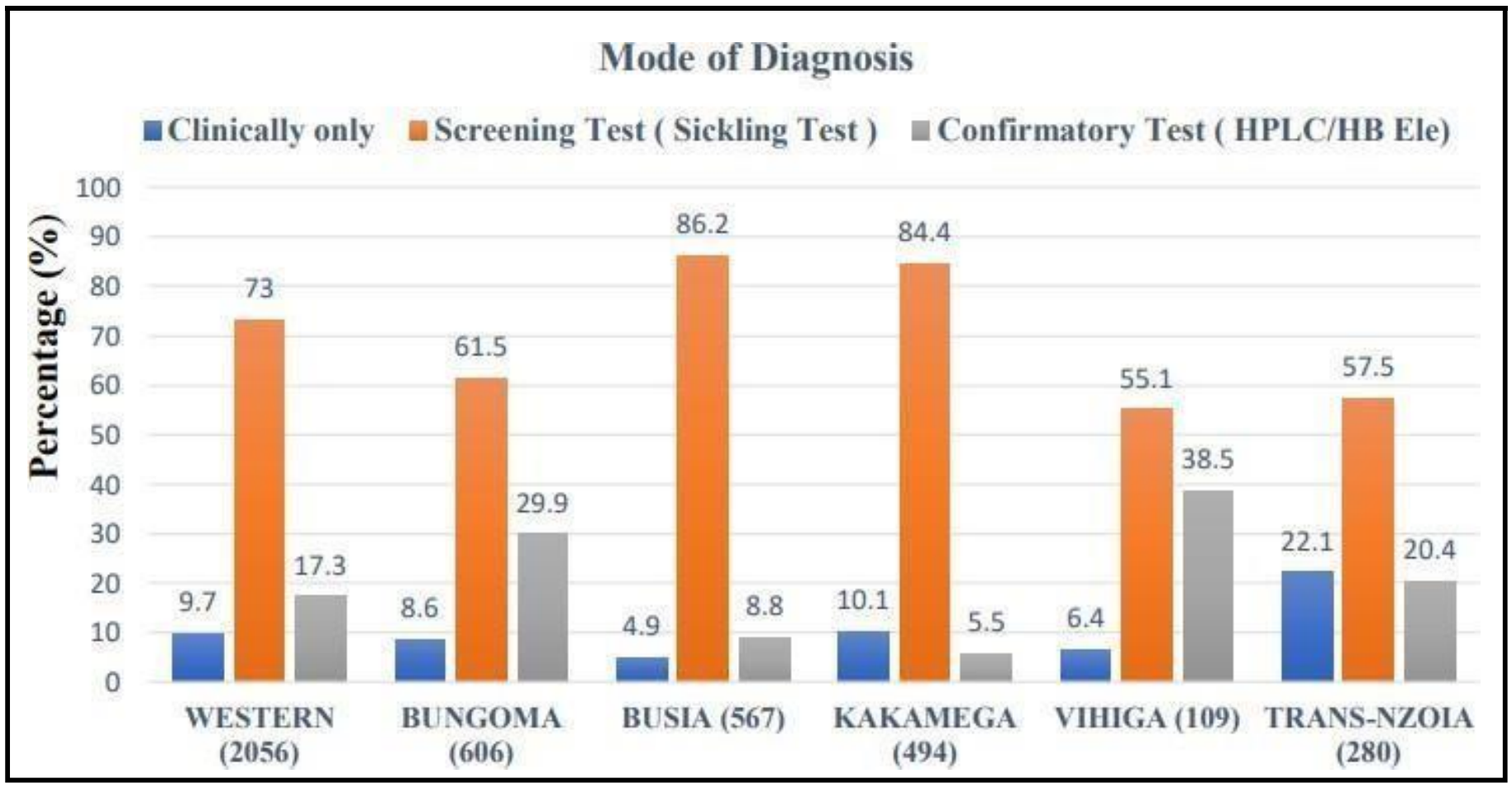


Table 16: Number and frequency of hospital admissions of PLWSCD

	WESTERN		BUNGOMA		BUSIA		KAKAMEGA		VIHIGA		TRANS-NZOIA	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Hospital Admissions (2056)												
No	283	13.8	94	15.5	93	16.4	42	8.5	18	16.5	36	12.9
YES	1773	86.2	512	84.5	474	83.6	452	91.5	91	83.5	244	87.1
Last 12 Months	1761	99.3	500	97.7	474	100	452	100	91	100	244	100
>12<24 Months	12	0.7	12	2.3	0	0	0	0	0	0	0	0
No of Admissions (1773)												
<5	868	49.0	217	42.4	199	42.0	246	54.4	67	73.6	139	57.0
5-9	564	31.8	172	33.6	178	37.6	125	27.7	7	7.7	82	66.6
10+	341	19.2	123	24.0	97	20.4	81	17.9	17	18.7	23	9.4

Table 17: Number and frequency of Blood Transfusions

	WESTERN		BUNGOMA		BUSIA		KAKAMEGA		VIHIGA		TRANS-NZOIA	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Ever Transfused (1773)												
No	128	7.2	35	6.8	41	8.7	25	5.5	13	14.3	14	9.7
YES	1645	92.8	477	93.2	433	91.3	427	94.5	78	85.7	230	90.3
<6 Months	1072	65.2	405	84.9	257	59.4	250	58.5	36	46.2	124	53.9
6 - 12 Months	573	34.8	72	15.1	176	40.6	177	41.5	42	53.8	106	46.1
12+	0	0	0	0	0	0	0	0	0	0	0	0
No of Blood Transfusion (1645)												
<5	838	50.9	237	49.6	19	44.8	232	54.3	54	69.2	121	52.6
5-9	503	30.6	145	30.4	143	33.0	110	25.8	13	16.7	92	40.0
10+	304	18.5	95	20.0	96	22.2	85	19.9	11	14.1	17	7.4

Table 18: Access to special Vaccines and Hydroxyurea by PLWSCD

	WESTERN		BUNGOMA		BUSIA		KAKAMEGA		VIHIGA		TRANS-NZOIA	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
Vaccines (2056)												
Meningococcal	15	0.7	1	0.2	5	0.9	2	0.4	4	3.7	3	1.1
Pneumococcal	107	5.2	28	4.6	18	3.2	22	4.6	6	5.5	33	11.8
None	1934	94.1	577	95.2	544	95.9	470	95.0	99	90.8	244	87.1
Medication (2056)												
Hydroxyurea	633	30.8	261	43.1	123	21.7	102	20.6	39	35.8	108	38.6
NO Hydroxyurea	1423	69.2	345	56.9	444	78.3	392	79.4	70	64.2	172	61.4

Narrative–Objective 3

- The Male to Female ratio was 1:1.1
- Majority (1745 ,84.7%) of the PLWSCD were aged less than 18 years.
- A total of 859 (41.8%) knew of a relative with SCD.
- Those who had ever had a medical cover were 941 (45.8%) out of which 730 (77.6%) were settling the premiums by direct remission to the fund while only 702 (34.1%) out of the total 2056 PLWSCD had a medical cover that was active and beneficial.
- Only 357(17.3%) had a confirmatory test done while 1500(73.0%) had a screening (sickling) test done to diagnose SCD.
- Majority (1773, 86.2%) of the PLWSCD had had multiple hospital admissions and multiple blood and blood product transfusions.
- Only 633(30.8%) out of the total 2056 PLWSCD were able to access and afford hydroxyurea.

Recommendations

i. Set up specialized clinics for SCD, continue registrations of PLWSCD and collect standardized information by using encounter (initial and return) forms. The information collected by the initial encounter forms (Appendix IV) will be useful for setting up a SCD registry. The standardized information collected by the return encounter forms (Appendix V) will be useful in working out intervention activities.
ii. Purchase and install relevant equipment for screening, diagnosis and monitoring.
iii. Facilitate and encourage families to enroll into a medical cover.
iv. Stock the medications and vaccines required by PLWSCD at an affordable price in order to make them accessible. Revolving fund services (laboratory and Pharmacy) are recommended.

2.4 Objective 4

Determination of The Haemoglobin Variants of Different Demographic Groups Including New Born.

This objective was not easy to test during the study period because of the fact that all the 5 pilot counties did not have machines (HPLC, HB Electrophoresis) for confirmatory test. However, by the time the study team was exiting the field, Bungoma County had acquired a HPLC machine while the rest of the 4 counties were in the process of sourcing for one each.

The process is on-going but data has not been collected and analysed. All the ethical procedures are to be taken into consideration and followed. The target population are all the residents in the included counties. Blood samples will be drawn from each of the participants through the appropriate standard sterile procedures and will be done by trained personnel.

The tests to be done will be agreed upon depending on the cost and availability. These will include the Point of Care (Haemotype SC or Sickle Scan) or confirmatory test (IEF, HPLC or Hb Electrophoresis). The relevant machines (Isoelectric Focusing, HB Electrophoresis, and High-Performance Liquid Chromatography) will be used to determine the different Haemoglobin variants. The relevant personnel will be trained to carry out the tests.

Screening centres (Newborn and other age groups) are to be set up in identified health facilities.

Purchase of the relevant test kits, equipment, machines, reagents, supplies and training of the required personnel is required for these crucial activities to be realised.

3.0 Discussion

Sickle Cell Disease (SCD) was first described in 1910 and later got its name in 1922. **[4]** Since then, a lot of discoveries have been made with regard to the cell biology, genetics, epidemiology, clinical features and its management. **[4]** In December 2008 at the 63rd session of the UNITED NATIONS(UN) general assembly SCD was described as "the world's foremost and lethal genetic disease" which requires global efforts "to bring the disease out of the shadows" **[4, 8, 9]**

The fact that SCD is a genetic disorder whose inheritance is autosomal recessive such that those who inherit the gene from both parents (Hb SS) suffer lifelong symptoms while those who inherit from one parent (Hb AS) are carriers who generally lead normal lives but can transmit the gene to their offspring is important information whose application can be a useful strategy in its control **[4, 8, 9]**.

The control of SCD requires the concurrent implementation of the WHO interventional strategies categorized into primary, secondary and tertiary in which appropriate care is given to those already born and living with SCD , Babies and infants are screened so that those found to have SCD are started on care early and public health education on SCD is provided, people are encouraged to test and know their haemoglobin variant/ genotype and therefore make informed choices about their lives, spouses and offspring with an aim of preventing birth of sicklers **[4, 6, 7, 9]** Programmes in the developed countries have been successful and have demonstrated that where they exist, survival of patients is steadily improving, affected births are falling and an increasing number of patients are stabilizing. **[4, 6, 7, 9]**. It is high time that the region also embraces this. The recommendation by WHO that at least 50 percent of member states should have established SCD control programmes by 2020 is a dream though overdue that should be realized by all African countries including Kenya and indeed TEAM (Together Each one Achieves More) work by all stakeholders is necessary in this situation. **[4, 9]**

This study found a low knowledge (4.9 out of 15) by HCPs on SCD in the pre-test. The average knowledge and mark improved to more than half (8.3 out of 15) the total mark in the post-test which was done soon after a 45-minute Continuous Medical Education (CME) session. The health care providers assessed were of different cadres

including community health workers, social workers, nurses, clinicians, doctors and etc. The initial low level of knowledge is an indication that majority of the HCPs are not equipped with the basic knowledge and skills on SCD and are therefore, unlikely to effectively play a significant role in the activities required for the control of SCD. The positive trends in improvement of knowledge observed is quite promising and that therefore calls for more CME sessions as well as the preparation and dissemination of standardized Information, Education and Communication (IEC) materials with specific messages in order to reach more health care providers and other communities.

This study evaluated a total of 76 health facilities out of which 67 (88.1%) were public and 68 (88.5%) were either level 3 or 4. With the understanding that 60 to 70 % of Kenyans seek for care in public facilities, the determination of the status of those facilities when taking into consideration the services to PLWSCD can assist in knowing the existing gaps and challenges that require to be addressed. All the 76 facilities were found to be NHIF accredited, had both laboratory and pharmacy departments as well as both medical (Doctors, Clinicians, Nurses, Laboratory officers, Pharmacists and etc.) and non-medical (security, hospitality, grounds people) staff. The available infrastructure and staff are a significant strength which should not be taken for granted but should provide the opportunity to improve care services.

The facilities which reported that they attend to SCD clients were 50(65.8%) but only 12(15.8%) were able to occasionally stock hydroxyurea which is the main medication required to manage SCD illustrating the frustrations that clients and care givers go through in seeking for care. These findings call for combined efforts by stakeholders to purchase the relevant equipment and reagents to capacitate the laboratories as well as stock the pharmacies with the required basic medications. Revolving fund services for the two departments whereby the bureaucracies encountered in the existing government procedures are avoided. This is a workable option to improve the accessibility, affordability and sustainability of the care services.

This study registered a total of 2056 PLWSCD in the 5 counties, majority of whom (1745,84.9%) were aged less than 18 years while only 23 (1.1%) were aged more than 45 years. This dependent group (children and students) on their parents or guardians accounted for 1632 (79.4%) of the participants, while those who were adults but unemployed were 395(19.2%) with only 29(1.4%) who had some form of employment. These findings indicate the challenges associated with a lifelong illness where the morbidity and mortality are high together with low levels of employment.

The PLWSCD who indicated that they knew of a relative with SCD were 859(41.8%) which confirms the fact that it is a genetic disease that can run in families if awareness is not created. To mitigate this situation, efforts to prevent further birth of more sicklers by utilization of the facts that inheritance of SCD is autosomal recessive, people need to test and know their genotype and therefore make informed choices about their spouses, offspring and lives are required. Meanwhile stakeholders should ensure that those already born and are living with SCD receive appropriate care.

This study found that out of the registered 2056 PLWSCD, 941 (45.8%) had ever had a medical cover with those having the cover active and beneficial being 702(34.1%). When asked about the mode of payment, 730 (77.6%) indicated that they remit directly to the fund (voluntary). These findings indicate low enrollment into the medical fund (NHIF) with majority (more than three quarters) enrolling directly on voluntary basis. Considering that SCD being a lifelong illness that requires frequent hospital visits and admissions, absence of a medical cover can have a negative socio-economic impact on families with PLWSCD. Efforts to encourage and support families to obtain medical cover as a priority activity are necessary. The coming on board of the Community Health Workers / Promoters (CHW/CHP) is timely for they can be tasked with the role of guiding families in putting together the documents required for enrolment and payment of the premiums into the medical fund.

This study found that in the diagnostic work up, only 357(17.3%) had had a confirmatory test (HPLC/Hb Electrophoresis), 1500 (73%) a screening test (sickling test) while 199(9.7%) had no laboratory diagnostic test done. These findings indicate the difficulties communities encounter in accessing the appropriate laboratory services. Efforts to equip the laboratories with the relevant machines and reagents are necessary.

This study found that out of the 2056 PLWSCD, 1773 (86.2%) had ever been admitted with the last admission occurring within the last 24 months with most of them having had multiple admissions. Out of those admitted, 1645(92.8%) had received blood transfusions within the last 12 months. These findings indicate the difficult medical journey experienced by PLWSCD who have to suffer a lifelong illness. This observation calls for mechanisms to provide blood and blood products as well as capacitate lower level (3 &4) health facilities with the basics.

In this study, only 633(30.8%) were able to access and afford Hydroxyurea which is the main drug used in the management of SCD and only 122(5.9%) had received either of the special vaccines (Pneumococcal 23 and Meningococcal) recommended for PLWSCD. These findings coincide with those in the evaluation of the health facilities whereby an average of 15.8% (12 out of 76) were able to stock Hydroxyurea. This further highlight the difficulties encountered by PLWSCD and their caretakers in accessing the basic medications and therefore calls for stakeholders to combine their efforts in ensuring accessibility, affordability and sustainability of the medical services required by the PLWSCD. The setting up of the revolving fund services (Pharmacy and Laboratory) is an option that should be considered as an appropriate way forward which can effectively sort

out the issues of accessibility and affordability.

The setting up and strengthening of existing specialized clinics for SCD and use of encounter forms (initial and return) to assist collect standardized data is what is required in order to have evidence and therefore work towards provision of effective services. The information collected by the initial encounter forms (Appendix IV) can provide data for the SCD registry while that collected in the return encounter forms (Appendix V) can be used as evidence for possible intervention activities.

4.0 Conclusion And Recommendation

4.1 Conclusion

1. Significant knowledge gaps on SCD among HCPs exist.
2. Health care facilities have good infrastructure, are NHIF accredited and have staff but are not able to provide the required services to PLWSCD because of lack of medicines, supplies and equipment.
3. Majority of the PLWSCD were aged less than 18 years, about one third had a medical cover.
4. Only a few (30.8%) could access and afford the medications required by PLWSCD.

4.2 Recommendations/ Call To Action

i. Enhance level of knowledge on SCD through CMEs, IEC materials and other forums.
ii. Purchase, stock and install the required medications, supplies, reagents and equipment in the health facilities.
iii. Encourage families to enroll and have medical insurance.
iv. Set up specialized clinics for sickle cell disease and collect standardized information (using encounter forms) that can be analysed and used for intervention.
v. Encourage the Ministry of Health and the County Health Management Teams to take leadership in the provision of the services.

Specialized clinics should be set up in health facilities where significant clusters of PLWSCD were registered. There should also be consideration of the distance between the health facilities whereby accessibility of the services by the clients is easily possible. The following are the tentative sites in order of priority in each of the counties.

Table 19: Tentative sites proposed for specialized clinics

	County				
	Bungoma	**Busia**	**Kakamega**	**Vihiga**	**Trans- Nzoia**
Registered No. of PLWSCD	**606**	**567**	**494**	**109**	**280**
1.	NAITIRI SCH (Tongaren)	AMUKURA SCH (Teso South)	NAVAKHOLO (Navakholo)	HAMISI (Hamisi)	MATUNDA (Kiminini)
2.	MALAKISI SCH (Bumula)	PORT VICTORIA SCH (Bunyala)	BUTERE (Butere)	EMUHAYA (Emuhaya)	ENDEBES (Endebes)
3.	CHWELE SCH (Kabuchai)	KHUNYANGU (Samia)	MATUNGU ((Matungu)	EBUSIRATSI (Luanda)	KAPSARA (Cherangany)
4.	KAPSOKWONY SCH (Mt. Elgon)	KOCHOLYA (Teso North)	LIKUYANI (Likuyani)		KWANZA (Kwanza)
5.	SIRISIA SCH (Sirisia)	MATAYOS (Matayos)	IGUHU (Ikolomani)		
6.	BUMULA SCH (Bumula)	ALUPE (Teso South)	MALAVA (Malava)		

Abbreviations And Acronyms

CHMT – County Health Management Team CME - Continuous Medical Education

Hb AA – Normal Haemoglobin Variant Hb AS - Haemoglobin variants of carriers

Hb SS – Haemoglobin variant of the warriors

HPLC – High Performance Liquid Chromatography. IEF-Iso Electric Focusing

PLWSCD – Persons living with Sickle Cell Disease. POC - Point of Care

RA- Registry Administrator SCA- Sickle Cell Anaemia SCD – Sickle Cell Disease SCT - Sickle Cell Trait

SCDRCP – Sickle Cell Disease Registries and Control Programme WHO – World

Appendix I - Registry Form D – SCD Organizations

SICKLE CELL FEDERATION OF KENYA
P.O. Box 9680-00300, Nairobi Kenya
Email: sicklecellfederationkenya@gmail.com
Phone Numbers:- +254 710 141 121 / +254 733 731 731

REGISTRY FORM D

SCD ORGANIZATIONS

Date : / /

A. PARTICULARS(Organization)

Name

Physical address:	P.O. Box:
Email:	Telephone numbers:

B. CATEGORY:

○ Non-Governmental Organization (NGO) ○ Faith Based Organization(FBO) ○ Institution
○ Support Group ○ Other (Specify):
Comments: -

C. LOCATION OF ACTIVITIES:

□ Continents.....	□ Counties.....
□ Countries.....	□ Towns .....

Comments:-

D. REPRESANTATION:

How many PLWSD does the organization represent?.....
How many PLWSCD have filled the registry Form A?.....

E. TYPES OF ACTIVITIES(Tick all that apply)

□ Advocacy □ Capacity building □ Support clients □ Research □ Other(Specify):
Comments:-

F. CONTACT PERSON:

First name: Middle name : Last name:

Designation:

Email:	Telephone numbers:

G. PAYMENT DETAILS:

Pay Bill No.: 522522	**Registration fee(ksh): 5000.**
Account Number 7588760	**Forward message to Mobile Number Airtel: - 0733 731 731 OR Safaricom: - 0710 141 121**

FORM FILLED BY (initials& sign) _____ DATE_____

COMPUTER ENTRY DONE BY _____ DATE_____

Sickle Cell Disease (SCD) Registry Form D- September, 2023.

MEMBERS(PLWSCD) OF THE ORGANIZATION				
	NAME	DESIGNATION	PHONE NUMBER	FILLED REGISTRY FORM A (YES/NO)

Sickle Cell Disease (SCD) Registry Form D- September, 2023.

Appendix II - Registry Form C – SFK Membership

SICKLE CELL FEDERATION OF KENYA
P.O. Box 9680-00300, Nairobi Kenya
Email: sicklecellfederationkenya@gmail.com
Phone numbers:-+254 710 141 121 / +254 733 731 731

REGISTRY FORM C

SICKLE CELL FEDERATION OF KENYA(SFK) MEMBERSHIP

Date: / /	**Membership No / ID No:** (Start with county no.)

A. DEMOGRAPHICS:

First name:	**Middle name:**	**Last name:**

D.O.B: / /	If DOB unknown estimated age in years:
Gender: ○ Male ○ Female	Address:
Email:	Phone number/s:

CURRENT RESIDENCE:

County:	Town:	Landmark: (Nearest School/Hospital/Church):

HOME DETAILS:

County:	Sub-County (Division):
Location	Sub-location
Village	Town:
Family/Clan name	Landmark (Nearest School/Hospital/Church):

Highest level of education: ○ None ○ Primary (completed) ○ Secondary (completed) ○ Tertiary (completed)

DESIGNATION (Tick all that apply)

□ PLWSCD □ Care Taker □ Health Care Provider □ Other(specify):

What is your Sickle cell status (Haemoglobin variant)?
□ Unknown (Not tested) □ Hb AA(Normal) □ Hb AS (Carrier) □ Hb SS (SC Disease)
□ Other(specify):

1

Sickle Cell Federation of Kenya (SFK) Membership Registry Form-C-May, 2023.

A.PLWSCD

1a. Have you filled the Registry Form A PLWSCD? ○ No ○ Yes
b. Are you a member of any other organization that deals with SCD? ○ No ○ Yes
c. If yes for member of any other organization dealing with SCD, specify details below:

2a. Do you belong to any support group/s? ○ No ○ Yes
b. If yes in 2a. above for any support group, specify details below:

3a. Are you under any Medical Cover? ○ No ○ Yes
b. Type of medical insurance cover? □ NHIF □ Other medical insurance cover(specify):
c. Enrollment mode to insurance cover? □ Automatic (Work place) □ Direct remission to fund □ Other(specify):

4. Where do you attend clinic?

B. CARE TAKER

1a. What is your relationship to PLWSCD? □ Father □ Mother □ Relative(specify): □ Institution(specify):
1b. How many PLWSCD do you take care of? _____

2a. Employment status? □ None □ Self-Employment □ Formal employment(professional) □ Other employment(specify):
b. Specify the details of employment in the choice/s selected in 2a. above:

C. HEALTH CARE PROVIDER

1a. Place of work: □ Public Health Facility □ Private Health Facility □ Faith based organization □ Other(specify):
b. County of work in 1a. above:
c. Name of institution in 1a. above:

d. Area of specialization: ○ Doctor ○ Clinical Officer ○ Nursing Officer ○ Nutritionist ○ Laboratory Technologist ○ Pharmaceutical Technologist ○ Social Worker ○ Psychiatrist ○ Health Records & Information Services Officer (HRIO) ○ Other(specify):

D. CATEGORIES OF MEMBERSHIP .

a. PLWSCD (No fee)
b. SFK officials (@1000 ksh.)
c. Other Members (@ 1000 ksh.)
d. Corporate Members (5,000 ksh.)

E. PAYMENT DETAILS

Pay Bill No.: 522522	**Registration fee(ksh):**
Account Number 7588760	**Forward message to Mobile Number Airtel: - 0733 731 731 OR Safaricom: - 0710 141 121**

2

Sickle Cell Federation of Kenya (SFK) Membership Registry Form-C-May, 2023.

Citation: Tenge CN, Nangami MN, Sorre BM, Okinyi FO, Liru MW, et al. (2025) Strengthening Evidence Based Management Of Sickle Cell Disease In A Control Programme By Setting Up Registries, Screening Services And Strengthening The Specialized Clinics In Five Pilot Counties Of Western Kenya. J Comm Med and Pub Health Rep 6(08): https://doi.org/10.38207/JCMPHR/2025/OCT06080159

Appendix III – Registry Form B for Hemoglobin Variants

MOI UNIVERSITY – CHS
P. O. Box 4606 - 30100, Eldoret, Kenya
Email:- principalchs@mu.ac.ke

SICKLE CELL FEDERATION OF KENYA
P.O. Box 9680-00300, Nairobi Kenya
Email: sicklecellfederationkenya@gmail.com.

SICKLE CELL DISEASE SCREENING
HAEMOGLOBIN VARIANT FORM- B

Screening Site:	Is the client a referral? □ No □ Yes if yes, indicate referring facility _____

1. Demographic Information

First name: Middle name Last name

Serial Number:	Telephone Contact:
Hospital Number:	Other Number:
D.O.B: / / Age (years)	Gender □Male □Female
County:	Sub County/Division/Constituency:
Location:	Sub-location:
Village:	Residence:
Family name/clan name:	Landmark: nearest Sch/Hosp/Church

2. Subject occupation □ N/A(Child) □ Student □ Unemployed □ Informal employment □ Formal /Professional employment **Specify**

5. Family Information

Number of siblings: Birth order(client) :

Are you under any medical cover? □ No □ Yes *If Yes,* □ NHIF □ Other(specify)?

Date of enrollment (medical cover) : / /

Mode of enrollment: □ Automatic/Place of work □ Direct remission to fund □ Other(specify):

Is the cover currently active and paid for? □ No □ Yes

Any relative(s) ever diagnosed with sickle cell disease: □ No □ Yes
If Yes, how many? :_____

Relationship	Name (initials)	Alive	Dead
1.		□	□
2.		□	□
3.		□	□
4.		□	□

Client's Screening Test Results:

IsoElectric Focusing	□ AA	□ AS	□ AC	□ SS	□ SC	□ CC	□ Other (Specify)
Hb Electrophoresis	□ AA	□ AS	□ AC	□ SS	□ SC	□ CC	□ Other (Specify)
High Performance Liquid Chromatography(HPLC)	□ AA	□ AS	□ AC	□ SS	□ SC	□ CC	□ Other (Specify)
Other (Specify)	□ AA	□ AS	□ AC	□ SS	□ SC	□ CC	□ Other (Specify)

Any other relevant information?

FORM FILLED BY (initials& sign) _____ DATE_____

COMPUTER ENTRY DONE BY (initials &sign)_____ DATE_____

INSTITUTIONAL RESEARCH & ETHICS COMMITTEE
29 AUG 2021
APPROVED
P. O. Box 4606 - 30100 ELDORET

HBV Screening Form

Ministry of Health

P.O Box 30016 – 00100 Nairobi, Kenya
Email: mohcommunication@health.go.ke

SICKLE CELL FEDERATION OF KENYA
P.O. Box 19676-00202, Nairobi Kenya
Email: sicklecellfederationkenya@gmail.com.

SICKLE CELL DISEASE SCREENING
HAEMOGLOBIN VARIANT FORM

Serial No.	Date	Screening site

1. Demographic Information

First name:	Middle name	Last name

Telephone Contacts

D.O.B: / / Age (years)	Gender □Male □Female
County:	Sub County
Village:	Residence:

Land mark: nearest SCH/Hosp/Church

2. Subject Occupation

□ N/A(Child) □ Student □ Unemployed □ Informal employment (Specify)
□ Formal /Professional employment Specify

3. Family Information

Are you under any medical cover? □ No □ Yes *If Yes,* □ NHIF □ SHIF □ Other(specify)?

Mode of enrollment: □ Automatic/Place of work □ Direct remission to fund □ Other(specify):
Is the cover currently active and paid for? □ No □ Yes

Any relative(s) ever diagnosed with sickle cell disease: □ No □ Yes
If YES, how many? : _____

4. Client's Test Results:

Test Type	□ Haemotype SC □ Sickle SCAN □ IEF □ HB Electrophoresis □ HPLC □ Other (Specify)
Haemoglobin Variant	□ AA □ AS □ SS □ Other (Specify)
Action Taken	Genetic Counselling done? □ NO □ YES Linkage to care done? □ NO □ YES □ N/A If Yes (Specify)

Any other relevant information?

FORM FILLED BY (initials& sign) _____ DATE_____

COMPUTER ENTRY DONE BY (initials &sign)_____ DATE_____

HBV Cliints Copy

Ministry of Health

P.O Box 30016 – 00100 Nairobi, Kenya
Email: mohcommunication@health.go.ke

SICKLE CELL FEDERATION OF KENYA
P.O. Box 19676-00202, Nairobi Kenya
Email: sicklecellfederationkenya@gmail.com

SICKLE CELL DISEASE SCREENING
HAEMOGLOBIN VARIANT FORM

Serial No.	Date	Screening site

1. Demographic Information

First name:	Middle name	Last name

D.O.B: / / Age (years)	Gender □Male □Female

2. Client's Test Results:

Test Type	□ Haemotype SC □ Sickle SCAN □ IEF □ HB Electrophoresis □ HPLC □ Other (Specify)
Haemoglobin Variant	□ AA □ AS □ SS □ Other (Specify)
Action Taken	Genetic Counselling done? □ NO □ YES Linkage to care done? □ NO □ YES □ N/A If Yes (Specify)

FORM FILLED BY (initials& sign) _____ DATE_____

Ministry of Health

P.O Box 30016 – 00100 Nairobi, Kenya
Email: mohcommunication@health.go.ke

SICKLE CELL FEDERATION OF KENYA
P.O. Box 19676-00202, Nairobi Kenya
Email: sicklecellfederationkenya@gmail.com

SICKLE CELL DISEASE SCREENING
HAEMOGLOBIN VARIANT FORM

Serial No.	Date	Screening site

1. Demographic Information

First name:	Middle name	Last name

D.O.B: / / Age (years)	Gender □Male □Female

2. Client's Test Results:

Test Type	□ Haemotype SC □ Sickle SCAN □ IEF □ HB Electrophoresis □ HPLC □ Other (Specify)
Haemoglobin Variant	□ AA □ AS □ SS □ Other (Specify)
Action Taken	Genetic Counselling done? □ NO □ YES Linkage to care done? □ NO □ YES □ N/A If Yes (Specify)

FORM FILLED BY (initials& sign) _____ DATE_____

1

HBV Summary Sheet

Ministry of Health
P.O Box 30016 – 00100 Nairobi, Kenya
Email: mohcommunication@health.go.ke

HAEMOGLOBIN VARIANT SUMMARY SHEET

SICKLE CELL FEDERATION OF KENYA
P.O. Box 19676-00202, Nairobi Kenya
Email: sicklecellfederationkenya@gmail.com.

S/No	NAME	SEX M/F	D.O.B	AGE (YRS)	COUNTY	SUBCOUNTY	TEL NO.	MED. COVER YES/NO	TEST NAME	TEST RESULT HB VARIANT

Appendix IV - Initial Encounter Form

Moi University- CHS
P. O. Box 4606 - 30100, Eldoret, Kenya
Email: principalchs@mu.ac.ke

SICKLE CELL FEDERATION OF KENYA
P.O. Box 53920-00200, Nairobi Kenya
Email: - sicklecellfederation@gmail.com

SICKLE CELL DISEASE(SCD) CLINIC
INITIAL ENCOUNTER FORM

Date: / /	Name of facility
1. Demographic Information	
First name: - Middle name	Last name:
Serial Number:	Telephone Contact:
Hospital Number:	Other Number:
D.O.B: / / Estimated Age Years	Gender □Male □Female
County:	Sub County/Division/Constituency:
Location:	Sub-location:
Village:	Residence:
Family name/clan name:	Landmark: nearest Sch/Hosp/Church

2. Person Accompanying Patient:
□ Self □ Mother □ Father □ Sibling □ Children's Home □ Grandparent (□Paternal □Maternal)
□ Auntie (□Paternal □Maternal) □ Uncle (□Paternal □Maternal) □ Other:

3. Subject /Patient occupation: - □ N/A(Child) □ Student □ Unemployed / Household
□ Employed (□ Informal □ Formal) **Specify**_____

4. Vitals:	RR _____ breaths/min	Pulse_____ beats/min	Temp [C°]_____	SaO_2_____%
	Wt _____kg	Height _____ cm	$BMI = \frac{Wt(Kg)}{Ht(M^2)}$ =	BP _____/_____

4. Maternal information		
Name (Initials):	□ Alive □ Dead	Date of Birth (DOB): / /
Highest level of education: □ None □ Primary (completed) □ Secondary ((completed) □ Tertiary (completed)		
Employment status: □ None/Household □ Employed (□ Informal □ Formal) **Specify**_____ □ Other(specify):_____		
Marital Status: □ Married (□ monogamous □ polygamous) □ Widowed □ Not married (□ Single □ Separated) □ Other(specify):		
5. Paternal information		
Name (Initials):	□ Alive □ Dead	Date of Birth (DOB): / /
Highest level of education □ None □ Primary(completed) □ Secondary(completed) □ Tertiary(completed)		
Employment status: □ None/Household □ Employed (□ Informal □ Formal) **Specify**_____ □ Other(specify): _____		
Marital Status: □ Married (□ monogamous □ polygamous) □ Widowed □ Not married (□ Single □ Separated)		

1

□ Other(specify):

6. Family Information

Number of siblings: Birth order(patient): sibling survival status: - Number Alive Number Dead

Is patient under any medical cover: □ No □ Yes *If Yes,* □ NHIF □ Other(specify):
Is it currently active and paid for: □ No □ Yes Does it cover sickle cell as an essential package? □ No □ Yes

Date of enrollment (medical cover): / /
Mode of enrollment: □ Automatic/Place of work □ Direct remission to fund □ Other(specify):

7. Any relative(s) ever diagnosed with sickle cell disease? □ No □ Yes *If Yes,* how many? _____

Relationship	Name (initials)	Alive	Dead
1.		□	□
2.		□	□
3.		□	□
4.		□	□
5.		□	□

8. Co- Morbidities

Does the client have any co-morbidity? □ No □ Yes (□ Diabetes □ Hypertension □ Asthma □ HIV □ Other)
Comments:-

Does client have any SCD related complication? □ No □ Yes (□ Stroke □ Thrombosis □ PH □ Organ Damage □ Other)
Comments:-

9. Community Health Worker (CHW)

Does Client's family identify with any CHW? □ No □ Yes (Name (s) Contact(s)
Comments: -

10. Physical Exam

Does Client have a disability? □ No □ Yes (□ Growth Faltering □ Cerebral Palsy □ Physical disability: □ Mental Disability □ Other)
Explain.

General Examination:	□ Normal	□ Abnormal	
Systems	□ Normal	□ Abnormal	□ CNS □ CVS□ RS □ PA □ GUS □ MSS□ Other

Comments:-

11. Investigations done

Diagnostic Tests:			**Comment/ Result**
Sickling Test	□ No	□ Yes	
Point of Care Test	□ No	□ Yes	
HB Electrophoresis	□ No	□ Yes	
HPLC	□ No	□ Yes	
Blood specimens :			
Haemogram	□ No	□ Yes	
LFTs	□ No	□ Yes	
RFTs	□ No	□ Yes	
HIV screening	□ No	□ Yes	
Other	□ No	□ Yes	
Radiology :			
CXR	□ No	□ Yes	
Abdominal ultrasound	□ No	□ Yes	

2

CT scan	□ No □ Yes	
Trans Cranial Doppler	□ No □ Yes	
Other tests		

12. Diagnosis

Date / Age of Diagnosis of SCD _____/_____/_____ **Years**

13. Management

Has client ever had hospital admissions? □ No □ Yes If yes?

	Number	Comments
Last 12 Months	_____	_____
>12< 24 Months	_____	_____
> 24 Months ago	_____	_____

Ever received blood transfusion? □ No □ Yes if yes, explain

	Number	Comments
Last 12 months	_____	_____
>12< 24 months	_____	_____
> 24 months ago,	_____	_____

Ever received any of the following vaccines?			**Date**	**Comments**
Pneumococcal	□ No	□ Yes		
Meningococcal	□ No	□ Yes		
Typhoid	□ No	□ Yes		
Other specify	□ No	□ Yes		

Ever used the following medications?

	currently	Before	Date started	Date stopped	Comments
Folate	□	□	/ /	/ /	
Pen V	□	□	/ /	/ /	
Hydroxyurea	□	□	/ /	/ /	
Paludrine	□	□	/ /	/ /	
Other specify:	□	□	/ /	/ /	

Where do you attend clinic? _____

Where would you like to attend Clinic _____

Any other relevant information?

Any other comments/concerns

Next appointment date: Weeks _____ Months _____ Date: / /

FORM FILLED BY (initials& sign) _____ DATE_____

COMPUTER ENTRY DONE BY _____ DATE_____

3

Appendix V - Return Encounter Form

Moi University- CHS
P. O. Box 4606 - 30100, Eldoret, Kenya
Email: principalchs@mu.ac.ke

SICKLE CELL FEDERATION OF KENYA
P.O. Box 53920-00200, Nairobi Kenya
Email: - sicklecellfederation@gmail.com

SICKLE CELL DISEASE (SCD) CLINIC

RETURN ENCOUNTER FORM

Date : / /	Name of facility			
Name (Initials) :	D.O.B	Telephone Contact:		
Hospital Number:	Other Number:			
Does patient have NHIF? □ No □ Yes	NHIF No. □Active □ Not Active			
1. Vitals:	RR _____ breaths/	Pulse_____ beats/min	Temp [C°]_____	SaO_2_____%
	Wt _____kg	Height _____ cm	BMI = $\frac{Wt(Kg)}{Ht(M^2)}$ =	BP ____/_____

2. Person Accompanying Patient:
□ Self □ Mother □ Father □ Sibling □ Children's Home □ Grandparent (□Paternal □Maternal)
□ Auntie (□Paternal □Maternal) □ Uncle (□Paternal □Maternal) □ Other:

CURRENT VISIT

Does patient have any current concerns? □ No (patient stable) □ Yes (specify)
Comments:-:

INTERCURRENT MEDICAL INFORMATION

Date of last visit .....
This visit: □ Scheduled □ Unscheduled (earlier than expected) □Unscheduled (later than expected)
Comments: -

Does the Client have any co-morbidity or SCD complication? □ No □ Yes
Comments: -

What medications does the patient take? (Tick all that apply)
□ Hydroxyurea □Pen V □Folate □ Anti-Malarial (Paludrine) □ Pain Killers □Others (specify)
Comments: -

Since the last visit did the patient take all the medications as prescribed by the HCP? □ Yes □ No
□ Hydroxyurea □Pen V □Folate □ Anti-Malarial (Paludrine) □ Pain Killers □Others (specify)
Comments: -

Since the last visit did the patient experience any illness that required any medical attention □ No □ Yes (explain)
Comments: -

Since the last visit was the patient transfused or get any blood products? □ No □ Yes (explain)
Comments:-

1

How was the hospital bill settled? □ Medical Insurance (NHIF) □Out of pocket(cash) □ Waived □Other(explain)
Comments:-

Since the last visit, did the patient interact with any Community Health Worker(CHW)? □ No □ Yes (□ Telephone □ Physical)
Comments.

PHYSICAL EXAMINATION

Does Client have a disability? □ No □ Yes (□ Growth Faltering □ Cerebral Palsy □ Physical d' ability:
□ Mental Disability □ Other)
Explain.

General Examination:	□ Normal □ Abnormal	
Systems	□ Normal □ Abnormal	□ CNS □ CVS□ RS □ PA □ GUS □ MSS□ Other

Comments:-

INVESTIGATIONS

Blood specimen
□ None □ BS for MPS □ Haemogram □ CRP □ LFTs □ RFTs
□ Other(specify)

Radiological
□X-Ray □ Ultrasound □ CT Scan □ Transcranial Doppler □ Other (specify)

Other specimen(s)
□ Urine □ Stool □ CSF □ Sputum □ Other (specify)

PRESCRIPTION

Hydroxyurea Dose.....
Pen V Dose .....
Folate Dose .....
Anti-Malarial (Paludrine) Dose .....
Pain killer Dose .....
Vaccines(specify).....
Other (specify Dose) .....

OTHER

Does patient require any referrals? □ No □ Yes.
□ Psychosocial counselling □Physiotherapy/Occupational Therapy □Nutrition
□ Specialist review (specify) □Other (specify)
Comments

Any other comments/concerns

Next appointment date: Weeks _____ Months_____ Date : / /

FORM FILLED BY (initials& sign) _____ DATE_____

COMPUTER ENTRY DONE BY _____ DATE _____

2

SCD Clinic Summary

Ministry of Health

P.O Box 30016 – 00100 Nairobi, Kenya
Email: mohcommunication@health.go.ke

SICKLE CELL FEDERATION OF KENYA
P.O. Box 19676-00202, Nairobi Kenya
Email: sicklecellfederationkenya@gmail.com.

SCD CLINIC ATTENDANCE SUMMARY

DATE ____________________ FACILITY NAME______________________________________

S/ NO.	NAME	SEX M/F	HOSPITAL NUMBER	NEW/ REVIST	MEDICAL COVER YES/NO	RETURN DATE

SUMMARY

Number Of Clients: - NEW ______________ REVISITS _____________ TOTAL_____________

Number With Medical Cover YES___________ NO__________________ TOTAL_____________

HYDROXYUREA available at facility (YES/ NO) _______________________________

Appendix VI – Questionnaire for evaluating Health Facilities

KEY INFORMANT INTERVIEWS HEALTH CARE PROVIDERS

COUNTY_____

NAME OF FACILITY_____

LEVEL OF FACILITY_____

TYPE OF HEALTH FACILITIES

PUBLIC ☐

MISSION / FAITH-BASED ☐

PRIVATE ☐

HEALTH FACILITY ATTENDS TO SCD CLIENTS Yes ☐ NO ☐

HEATH FACILITY HAS LABORATORY DEPARTMENT YES ☐ NO ☐

HEATH FACILITY HAS PHARMACY DEPARTMENT YES ☐ NO ☐

HEALTH FACILITY IS NHIF ACCREDITED YES ☐ NO ☐

HEALTH FACILITY HAS MEDICAL STAFF YES ☐ NO ☐

HEATH FACILITY HAS SUPPORT STAFF YES ☐ NO ☐

COMMENTS.....

IS THERE A RELIABLE SUPPLY OF THE FOLLOWING DRUGS USED IN PATIENTS WITH SCD?

DRUG	YES	NO	COMMENT
FOLATE			
PEN V			
PALUDRINE			
HYDROXYUREA			
PNEUMOCOCCAL VACCINE			
OTHER			

COMMENTS.....

IS THERE ANYTHING YOU FEEL SHOULD BE DONE TO IMPROVE THE CONTROL OF SCD IN THE COUNTY

.....

.....

Appendix VII - Understanding SCD Pamphlet.

Tips for healthy living with SCD

Find good medical care
Sickle cell disease is a complex disease. Good quality medical care from health care providers who know a lot about the disease can help prevent some serious problems.

Get regular checkups
Regular health checkups with a health care provider can help prevent some serious problems.

Prevent infections
Common illnesses, like malaria or influenza can quickly become dangerous for a person with SCD. The best defense is to take simple steps like washing your hands frequently to help prevent infections.

Learn healthy habits
Drinking 8 to 10 glasses of water every day and eating healthy balance diet will help to maintain hydration and proper nutrition. People with SCD should maintain a balanced body temperature, getting neither too hot nor too cold.

Get support
Find a patient support group or community-based organization that can provide information, assistance, and support.

Preventive measures for SCD

Vaccines
Vaccines are a great way to prevent many serious infections. PLWSCD should have influenza, pneumococcal, meningococcal vaccine and any others recommended by their health care provider.

Penicillin
Penicillin can help prevent infections. Children with SCD should take penicillin or another antibiotic as prescribed by a health care provider

Proper hygiene & food safety
Good hygiene prevents spread of infections. Wash your hands using soap and clean water. Ensure proper handling of food like washing vegetables and fruit well before eating. Cook food appropriately.

Always drink **fresh fruit juices or water**.
Avoid drinks preserved with chemicals like sodium metabisulphite.

Avoid handling wild animals like Reptiles
Salmonella is present in some reptiles and can be especially harmful to people with SCD. Make sure children and adults stay away from turtles, snakes, and lizards.

Register for NHIF & Linda mama for affordable health care.

For more information contact: dncdldepartment@gmail.com | +254 20 2717077

Kenya Haemophilia Association · Health Promotion · HB · sysmex · Alliance (K) · ampath · novo nordisk haemophilia foundation · novo nordisk fonden · NOVARTIS

MINISTRY OF HEALTH

UNDERSTANDING SICKLE CELL DISEASE

"Screen and care for Sickle Cell Disease.

Tambua Hali Yako.

What is Sickle Cell disease (SCD) ?

SCD is a genetic/inherited illness that affects the red blood cells.
This means it can be passed on from the parents to their offspring. One can be born with it but cannot get infected from other people.

Inheritance - Autosomal Recessive:
Gene from both parents - Express symptoms
Gene from one parent - Carrier state

Haemoglobin Variants / Types of SCD:
There are about 1200 types but most have no clinical significance:
Hb AA - Normal Haemoglobin
Hb AS - Sickle Cell Trait/ Carrier
- Generally lead normal lives.
- Most are NOT aware they carry the gene.
- Have the potential to transmit the gene to their offspring.

Hb SS- Sickle Cell Anaemia/ Warrior / PLWSCD
- Have life long symptoms (Anaemia, Vaso-Occlusion or Organ damage).
- Transmit the gene to their offspring.

The percentage chance that a pregnancy will result into an offspring with sickle cell anaemia (Hb SS) is 25 percent if both parents are carriers (Hb AS), 50 percent if one parent is a carrier and the other a warrior (Hb AS & Hb SS) and 100 percent if both parents are warriors (Hb SS).

HAEMOGLOBIN VARIANT (PARENTS)		Percentage Chance Per Pregnancy (OFFSPRING)		
		Normal Hb AA	Carrier Hb AS	Disease Hb SS
Hb AA	Hb AA	100	-	-
Hb AA	Hb AS	50	50	-
Hb AA	Hb SS	-	100	-
Hb AS	Hb AS	25	50	25
Hb AS	Hb SS	-	50	50
Hb SS	Hb SS	-	-	100

Symptoms of SCD ?

- **Chronic (long term) Anaemia** - when there are not enough red blood cells or Hb in your body.
- Tiredness, feeling weak or experience fatigue.
- **Jaundice** - yellowing of the whites of the eyes and skin.
- **Pain**- Sickle cells don't move easily through small blood vessels and can get stuck and clog the blood flow. This causes pain that can start suddenly, be mild to severe, and last for any length of time.
- **Acute Chest Syndrome** - Blockage of the flow of blood to the lungs can cause acute chest syndrome. This complication is similar to pneumonia symptoms which include chest pain, coughing, difficulty breathing, and fever. It can be life-threatening and should be treated in a hospital.
- **Hand or Foot problem** - Swelling in the hands and feet, often along with a fever, is caused by the sickle cells getting stuck in the blood vessels and blocking the blood from flowing freely through the hands and feet.
- **Stroke** - Sickle cells can clog blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.
- **Infection** - People with SCD, especially infants and children, are more likely to experience harmful infections such as flu, meningitis, and hepatitis.
- **Organ damage** - Eyes, Heart, Kidneys, Bones, Lungs, Spleen etc. SCD can affect the blood vessels in the organs and lead to long term damage.

Tests /diagnosis for SCD

- **Screening Tests/ Preliminary tests** - Sickling test, Point of Care and Complete blood count.

They are available in sub county and county referral hospitals.

- **Confirmatory Tests** - HPLC- High Performance Liquid Chromatography, Hb Electrophoresis, IEF - Isoelectric Focusing.

They are available in Bungoma CRH, MTRH, Baraka HC Mathare, JOOTRH.

Management of SCD

The Ministry of Health has provided guidelines which are categorized into Primary, Secondary and Tertiary interventional strategies.

- The primary interventional strategy aims at **preventing birth of Sicklers** and targets those who plan to have families in future. It entails educating people about SCD. People are **encouraged to test and know their sickle cell status** (HbAA, HbAS or HbSS) and make informed choices about their lives, spouses and offspring. Those who carry the gene (HbAS & HbSS) are advised to pair up with those who are carrying the normal gene (HbAA) so that they do not get offspring with SCA (HbSS).

- The secondary interventional strategy targets families in high burden counties that are likely to get offspring born with sickle cell disease. Screening is done to identify those born with SCD who need specialized care.

- The Tertiary interventional strategy refers to any care given to PLWSCD. They can present with acute illnesses (Anaemia, painful crisis, infections, acute chest syndrome or stroke) or chronic complications (damage to the bones, eyes heart, kidneys, etc.). The PLWSCD are advised to attend specialized clinics regularly and take the prescribed medicines. The PLWSCD are also advised to enroll with NHIF and Linda Mama which can assist in settling hospital bills whenever they are admitted.

Appendix VIII -Test Questions and Explanations

TEST QUESTIONS- SCDRCP

Serial No. _____ **Name Initials**_____
Designation: Doctor ☐ Pharmacist ☐ Clinical Officer ☐ Nursing Officer ☐
Public Health Officer ☐ Other, specify_____
Date of Birth /Age (years) _____
Date of Employment / Years in Service_____

SECTION A

1. **The first description of sickle cell was in year**
   a. 1861
   b. 1910
   c. 1922
   d. DO NOT KNOW

2. **The disease was named 'Sickle Cell Anemia' in the year**
   a. 1861
   b. 1910
   c. 1922
   d. DO NOT KNOW
3. **The yearly world sickle cell day is usually observed/ commemorated on**
   a. 19th June
   b. 1st April
   c. 2nd December
   d. DO NOT KNOW

4 **Sickle Cell Awareness month is**
   a. June
   b. September
   c. October
   d. DO NOT KNOW

*The first description of sickle cells was in **1910** by a Chicago Cardiologist and Professor of Medicine, Jam B Herrick (1861-1954) whose intern Ernest Edward Irons (1877-1959) found 'peculiar elongated and sickle-shaped' cells in the blood of a dental student at the Chicago College of Dental Surgery who was admitted to the Chicago Presbyterian hospital suffering from recurrent anaemia. The disease was named 'sickle cell anaemia' by Verne Mason in **1922,** then a medical resident at John Hopkins Hospital.*
*Each year on **June 19th**, countries all over the world commemorate the world sickle cell day, which was initially presented as a resolution by the United Nations in 2008.The goal of this day is to recognize SCD a a public health problem and promote education about the genetic condition. **September** is National sickle cell awareness month, designated by congress to help focus attention on the need for research and management of SCD.*

1

SECTION B

5. **Sickle Cell Disease is a genetic or hereditary blood disorder of the**
   a. Platelets
   b. White blood cells
   c. Red Blood cells
   d. DO NOT KNOW.

6. **Mode of Inheritance of Sickle Cell Disease is by**
   a. Autosomal dominant
   b. Autosomal recessive
   c. X – Linked recessive
   d. DO NOT KNOW

7. **Globin Chain production of cells is controlled by gene clusters found on chromosomes**
   a. 11 and 16
   b. 8 and 22
   c. 6 and 21
   d. DO NOT KNOW

*SCD is a genetic or hereditary blood disorder characterized by **red blood cells** that assume an abnormal, rigid sickle shape (sickling) in conditions of low oxygen concentration like dehydration, acidosis, infection, etc. Haemoglobin comprises of a haem group and four globin chains. Genes clusters on **chromosome 16 and 11** control globin chain production. Sickle Cell Disease is inherited in an **autosomal recessive** fashion. Any person carrying the sickle cell gene can transmit it to his or her offspring. Two categories of such persons exist –*

- *Those who have inherited the gene from one parent and are referred to as sickle cell carriers or have the Sickle Cell Trait (**SCT** or **Hb AS**). They lead normal lives and therefore **do not show any signs of the disease and are often unaware that they carry the gene**.*
- *Those who have inherited the gene from both parents and are referred to as having Sickle Cell Anaemia (**SCA** or **Hb SS**). They have **lifelong signs of sickness** which include anaemia (lack of blood), occlusion of blood vessels leading to painful episodes, stroke and chronic damage to various organs like the lungs, heart, joints especially the hip and kidneys.*

		Percentage Chance Per Pregnancy (OFFSPRING)		
Hb Variant (PARENTS)		Normal Hb AA	Carrier Hb AS	Disease Hb SS
Hb AA	Hb AA	100	-	-
Hb AA	Hb AS	50	50	-
Hb AA	Hb SS	-	100	-
Hb AS	Hb AS	25	50	25
Hb AS	Hb SS	-	50	50
Hb SS	Hb SS			100

2

SECTION C

8. If one parent has normal haemoglobin (Hb AA) and the other one has the sickle cell trait (Hb AS), the percentage chance that a pregnancy will result in an offspring with normal haemoglobin (Hb AA) is
   a. 0
   b. 25
   c. 50
   d. DO NOT KNOW

9. If one parent has normal haemoglobin (Hb AA) and the other one has the sickle cell trait (Hb AS), the percentage chance that a pregnancy will result in an offspring with the sickle cell Trait (Hb AS) is
   a. 0
   b. 25
   c. 50
   d. DO NOT KNOW

10. If one parent has normal haemoglobin (Hb AA) and the other one has the sickle cell trait (Hb AS), the percentage chance that a pregnancy will result in an offspring with the sickle cell anaemia (Hb SS) is
    a. 0
    b. 25
    c. 50
    d. DO NOT KNOW

If one parent has normal haemoglobin (Hb AA) and the other one has the sickle cell trait (Hb AS), the percentage chance that a pregnancy will result in an offspring with normal haemoglobin ***(Hb AA) is 50%,*** *with SCT* ***(Hb AS) is 50%*** *while with Sickle cell anaemia* ***(Hb SS) is 0%.***

SECTION D

11. If one parent has normal haemoglobin (Hb AA) and the other one has the sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result in an offspring with normal haemoglobin (Hb AA) is
    a. 0
    b. 50
    c. 100
    d. DO NOT KNOW

12. If one parent has normal haemoglobin (Hb AA) and the other one has the sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result in an offspring with the sickle cell trait (Hb AS).
    a. 0
    b. 50
    c. 100
    d. DO NOT KNOW

3

13. **If one parent has normal haemoglobin (Hb AA) and the other one has the sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result in an offspring with sickle cell anaemia (Hb SS) is**
    a. 0
    b. 50
    c. 100
    d. DO NOT KNOW

*If one parent has normal haemoglobin (Hb AA) and the other one has the sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result in an offspring with normal haemoglobin **(Hb AA) is 0%**, with SCT **(Hb AS) is 100%** and sickle cell anaemia **(Hb SS) is 0%***

SECTION E

14. **If both parents have the sickle cell trait (Hb AS), the percentage chance that a pregnancy will result into an offspring with normal haemoglobin (Hb AA)** is
    a. 0
    b. 25
    c. 50
    d. DO NOT KNOW

15. **If both parents have the sickle cell trait (Hb AS), the percentage chance that a pregnancy will result into an offspring with the sickle cell trait (Hb AS)** is
    a. 0
    b. 25
    c. 50
    d. DO NOT KNOW

16. **If both parents have the sickle cell trait (Hb AS), the percentage chance that a pregnancy will result into an offspring with sickle cell anaemia (Hb SS)** is
    a. 0
    b. 25
    c. 50
    d. DO NOT KNOW

*If both parents have the sickle cell trait (Hb AS), the percentage chance that a pregnancy will result into an offspring with normal haemoglobin **(Hb AA) is 25%**, with SCT **(Hb AS) is 50%** and sickle cell anaemia **(Hb SS) is 25%***

SECTION F

17. **If one parent has the sickle cell trait (Hb AS) and the other one has the sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result in an offspring with normal haemoglobin (Hb AA) is**
    a. 0
    b. 50
    c. 100
    d. DO NOT KNOW

4

18. If one parent has the sickle cell trait (Hb AS) and the other one has the sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result in an offspring with the sickle cell trait (Hb AS) is

a. 0
b. 50
c. 100
d. DO NOT KNOW

19. If one parent has the sickle cell trait (Hb AS) and the other one has the sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result in an offspring with sickle cell anaemia (Hb SS) is

a. 0
b. 50
c. 100
d. DO NOT KNOW

If one parent has the sickle cell trait (Hb AS) and the other one has the sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result in an offspring with normal haemoglobin ***(Hb AA) is 0%,*** *with SCT* ***(Hb AS) is 50%*** *and Sickle cell anaemia* ***(Hb SS) is 50%.***

SECTION G

20. If both parents have sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result into an offspring with normal haemoglobin (Hb AA) is

a. 0
b. 50
c. 100
d. DO NOT KNOW

21. If both parents have sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result into an offspring with the sickle cell trait (Hb AS) is

a. 0
b. 50
c. 100
d. DO NOT KNOW

22. If both parents have sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result into an offspring with sickle cell anaemia (Hb SS) is

a. 0
b. 50
c. 100
d. DO NOT KNOW

If both parents have sickle cell anaemia (Hb SS), the percentage chance that a pregnancy will result into an offspring with normal haemoglobin ***(Hb AA) is 0%,*** *with SCT* ***(Hb AS) is 0%*** *while sickle cell anaemia* ***Hb SS is 100%.***

5

SECTION H

23. The percentage of cases of sickle cell disease that Africa accounts for is

a. 10 to 40
b. 75 to 85
c. 3 to 4
d. DO NOT KNOW

24. The estimated number of infants born with sickle cell anaemia globally each year is

a. 300,000 to 400,000
b. 10 to 40 million
c. 75 t0 85 million
d. DO NOT KNOW

25. The percentage of individuals with sickle cell trait (Carrier frequency) across equatorial Africa is

a. 10 to 40 percent
b. 75 to 85 percent
c. 3 to 4 percent
d. DO NOT KNOW

26. The following is NOT a high burden region with SCD in Kenya

a. Western
b. Nyanza
c. North Eastern
d. DO NOT KNOW

27. The following is a high burden region with SCD in Kenya

a. Rift Valley
b. Coast
c. North Eastern
d. DO NOT KNOW

*Sickle Cell Disease (SCD) affects millions of people throughout the world. More than three quarters (75-85%) of the cases occur in Africa with an estimate of **300,000 to 400,000** infants born with SCD annually-affecting up to **3% of the births**. The carrier frequency ranges between **10% to 40%** across equatorial Africa. In Kenya, most of the cases are found in **Western, Nyanza, Coast, Nairobi** and parts of Eastern regions or provinces.*

SECTION I

28. The following is a preliminary test for Sickle Cell Disease

a. Sickling test
b. Hb Electrophoresis
c. Peripheral Blood Film (PBF)
d. DO NOT KNOW

29. The following is a preliminary test for Sickle Cell Disease

a. Reticulocyte count
b. Hb Electrophoresis
c. IsoElectric Focusing
d. DO NOT KNOW

6

30. The following is a screening test for Sickle Cell Disease

a. Sickling test
b. Hb Electrophoresis
c. High Performance Liquid Chromatography
d. DO NOT KNOW

31. The following is a Point of Care (POC) test for Sickle Cell Disease

a. Haemotype SC test
b. Hb Electrophoresis
c. High Performance Liquid Chromatography
d. DO NOT KNOW

32. The following is a Point of Care (POC) test for Sickle Cell Disease

a. IsoElectric Focusing
b. Sickle SCAN test
c. High Performance Liquid Chromatography
d. DO NOT KNOW

33. The following is a confirmatory test for Sickle Cell Disease

a. Sickling test
b. Sickle SCAN test
c. High Performance Liquid Chromatography
d. DO NOT KNOW

34. The following is a confirmatory test for Sickle Cell Disease

a. Hb Electrophoresis
b. Haemotype SC
c. Sickle SCAN test
d. DO NOT KNOW

The diagnosis of SCD is based on clinical presentation, personal and family history, clinical features (signs/symptoms) and laboratory testing (preliminary, screening or confirmatory tests)

*Preliminary or initial tests (**CBC, PBF, Reticulocyte count**) give general findings before validation of a health problem.*

*The screening tests (**sickling test, Haemotype SC, SickleScan**) detect potential health disorders in people who do not necessarily have any symptoms of the disease. The Haemotype and SickleScan are also point of care test.*

*The confirmatory tests (**High Performance Liquid Chromatography, HB Electrophoresis, Iso Electric Focusing**) confirm or rule out a medical condition with concerning symptoms or an out-of-range screening test. They can quantify the different haemoglobins and identify accurately other forms of SCD such as Hb S β-thalassaemia, Hb SC, Hb CC and etc.*

7

SECTION J

35. A person who has the sickle cell trait (Hb AS)

a. Has lifelong symptoms of anemia, Vaso-occlussion and chronic organ damage
b. Generally, leads a normal life
c. Has no potential of transmitting gene to offspring
d. DO NOT KNOW

36. A person who has the sickle cell anaemia (Hb SS)

a. Has lifelong symptoms of anemia, Vaso-occlussion and chronic organ damage
b. Generally, leads a normal life
c. Has no potential of transmitting gene to offspring
d. DO NOT KNOW

Any person carrying the sickle cell gene can transmit it to his or her offspring. Two categories of such persons exist –

- *Those who have inherited the gene from one parent and are referred to as sickle cell carriers or have the Sickle Cell Trait (**SCT** or **Hb AS**). They lead normal lives and therefore **do not show any signs of the disease and are often unaware that they carry the gene**.*
- *Those who have inherited the gene from both parents and are referred to as having Sickle Cell Anaemia (**SCA** or **Hb SS**). They have **lifelong signs of sickness** which include anaemia (lack of blood), occlusion of blood vessels leading to painful episodes, stroke and chronic damage to various organs like the lungs, heart, joints especially the hip and kidneys.*

SECTION K

37. The TERTIARY interventional strategy in the control of SCD according to the WHO (2006) guidelines entails

a. Managing complications by giving appropriate care to those who have sickle cell anaemia (Hb SS)
b. Newborn screening, follow up and provision of prophylactic management in order to prevent complications
c. Public Health Education, pre-conception genetic counselling and reproductive choices
d. DO NOT KNOW.

38. The SECONDARY interventional strategy in the control of SCD according to the WHO (2006) guidelines entails

a. Managing complications by giving appropriate care to those who have sickle cell anaemia (Hb SS)
b. Newborn screening, follow up and provision of prophylactic management in order to prevent complications
c. Public Health Education, pre-conception genetic counselling and reproductive choices
d. DO NOT KNOW

39. The PRIMARY interventional strategy in the control of SCD according to the WHO (2006) guidelines entails

a. Managing complications by giving appropriate care to those who have sickle cell anaemia (Hb SS)
b. Newborn screening, follow up and provision of prophylactic management in order to prevent complications
c. Public Health Education, pre-conception genetic counselling and reproductive choices
d. DO NOT KNOW

8

*The intervention strategies for SCD are categorized into **primary, secondary** and **tertiary** by the World Health Organization (WHO). The **tertiary** intervention entails managing the complications as the patients present with the signs and symptoms. The **secondary** intervention entails screening the newborns, identifying those with SCD, follow them up and provide prophylactic management. The **primary** intervention entails preventing birth of sicklers by ensuring persons are aware of their carrier status, there is pre-conception genetic counselling and reproductive choices made. In order to be effective, all these intervention strategies should be carried out **concurrently** in an organized manner and in a **SCD Control Programme**.*

SECTION L

40. In sickle cell disease care, prophylactic Pen V should be started at the age of

a. 2 months
b. 9 months
c. 5 years
d. DO NOT KNOW

41. The following supplement is recommended in the care of SCD

a. Iron
b. Folate
c. Magnesium sulphate
d. DO NOT KNOW

42. In sickle cell disease care, current recommendations are such that use of Hydroxyurea should be started at age

a. 2 months
b. 9 months
c. 5 years
d. DO NOT KNOW

*Infants diagnosed with SCD should receive standard well-child care. This includes the standard vaccines prescribed for all children. They should be referred for care in a specialized clinic whereby as early as the age of **2 months**, they are started on folate and Pen V and then at the age of **9 months** are started on hydroxyurea.*

SECTION M

43. 'RESPECT OF PERSONS' is an Ethical Principle in research that deals with

a. Individual autonomy and protecting individuals with reduced autonomy.
b. Risk and benefits with the aim of minimizing risks.
c. Equitable distribution of burdens and benefits.
d. DO NOT KNOW.

44. 'BENEFICENCE' is an Ethical Principle in research that deals with

a. Individual autonomy and protecting individuals with reduced autonomy.
b. Risk and benefits with the aim of minimizing risks.
c. Equitable distribution of burdens and benefits.
d. DO NOT KNOW.

Citation: Tenge CN, Nangami MN, Sorre BM, Okinyi FO, Liru MW, et al. (2025) Strengthening Evidence Based Management Of Sickle Cell Disease In A Control Programme By Setting Up Registries, Screening Services And Strengthening The Specialized Clinics In Five Pilot Counties Of Western Kenya. J Comm Med and Pub Health Rep 6(08): https://doi.org/10.38207/JCMPHR/2025/OCT06080159

45. 'JUSTICE' is an Ethical Principle in research that deals with
    a. Individual autonomy and protecting individuals with reduced autonomy.
    b. Risk and benefits with the aim of minimizing risks.
    c. Equitable distribution of burdens and benefits.
    d. DO NOT KNOW.

Research should be designed and conducted in a way that respects the rights, interests, values, dignity and autonomy of the participants (including individuals, groups and communities). Ethical issues are most likely to arise around privacy, equality, diversity and health safety. The following ethical principles govern research
***Respect for persons**- people should be treated as autonomous and those with diminished autonomy should be protected.*
***Beneficence-** Do no harm and maximize the benefits and minimize the risks for the participants.*
***Justice**- Equitable distribution of the burdens and benefits.*

SECTION N

46. The study participant/ subject required to sign a 'CONSENT' is
    a. Person aged above 18 years.
    b. Child aged above 7 years.
    c. Both child aged above 7 years and guardian /parent aged above 18 years.
    d. DO NOT KNOW.

47. The study participant/ subject required to sign an 'ASSENT' is
    a. Person aged above 18 years.
    b. Child aged above 7 years.
    c. Both child aged less than 7 years and guardian /parent aged above 18 years.
    d. DO NOT KNOW.

***A study participant/ subject** is an individual **whose** data, biological materials, or responses to interventions, stimuli, or questions by a researcher are relevant to answering the research question. Consent is a founding principle of research ethics. Its intent is that the human participants can enter research freely(voluntarily) with full information about what it means for them to take part, and they give consent before they enter the research.*
The assent process is an ongoing, respective and interactive conversation between the researcher and the child, young adult or adult lacking the capacity to give informed consent.
*Consent is signed by adults aged **eighteen (18) years and above** and by a parent/ guardian whose child is aged seventeen (17) years or below if the child is involved in a research study. Assent is signed by study subjects **aged less than 18 years and more than 7 years.***

SECTION O

48. Which of the following statements is TRUE about the sickle cell disease management situation in Kenya?
    a. The are NO Sickle Cell Disease management guidelines available.
    b. Confirmatory test (HB Electrophoresis/ HPLC) machines are available in all counties.
    c. There is need for a comprehensive Sickle Cell Disease control programme.
    d. DO NOT KNOW

10

49. Which of the following statements is TRUE about the sickle cell disease management situation in Kenya?

a. Sickle Cell Disease management guidelines were launched and are available.
b. Confirmatory test (HB Electrophoresis/ HPLC) machines are available in all counties.
c. There is a comprehensive Sickle Cell Disease control programme.
d. DO NOT KNOW

50. Which of the following statements is FALSE about the sickle cell disease management situation in Kenya?

a. There are Sickle Cell Disease management guidelines available.
b. Confirmatory test (HB Electrophoresis/ HPLC) machines are available in all counties.
c. There is need for a comprehensive Sickle Cell Disease control programme.
d. DO NOT KNOW

*The first draft of the sickle cell management guidelines was launched on **29th July 2021**. There is need for implementation of a comprehensive sickle cell disease control programme. Confirmatory test equipment (Hb Electrophoresis/ HPLC) is NOT available in majority of the counties in Kenya.*

11

Funder

- Moi University – College Of Health Sciences Research Development Fund (RDF)
- Department Child Health & Paediatrics (CHAP) School of Medicine

Researchers

- **Professor Constance Nalianya Tenge** is the Principal Investigator of the Sickle Cell Disease Registries and Control Programme (SCDRCP). She is a Paediatrician and Professor of Paediatrics at the Moi University, College of Health Sciences, School of Medicine, Department of Child Health and Paediatrics. She is a member of the Sickle Cell Federation of Kenya (SFK) where she serves as the chair of the scientific committee.
- **Professor Mabel Namubuya Nangami** is a Co- Principal Investigator of the SCDRCP. She is an Associate Professor of Health Policy and Health Systems management at the Moi University, School of Arts and Social Sciences (SASS). She is a member of the Sickle Cell Federation of Kenya (SFK).
- **Professor Benard Mwori Sore** is a Co- Principal Investigator of the SCDRCP. He is an Associate Professor of Anthropology at the Moi University, School of Arts and Social Sciences (SASS), Department of Sociology, Psychology and Anthropology. He is a member of the Sickle Cell Federation of Kenya (SFK).
- **Dr. Fredrick Otieno Okinyi** is a Co- Investigator of the SCDRCP. He is a Consultant Clinical Pathologist and Haematologist in Kenyatta National Hospital and a Lecturer at the University of Nairobi, School of Medicine, Department of Pathology. He is the chairman of the Sickle Cell Federation of Kenya (SFK).
- **Dr. Meshack Wekesa Liru** is a Co- Investigator of the SCDRCP. He is a Paediatrician and Child Health Specialist in Homabay County, Kenya. He serves as a member of the Scientific Committee of the Sickle Cell Federation of Kenya (SFK).
- **Mr. Maurice Shilabula** is a Co- Investigator of the SCDRCP. He is a Programmer and Information and Communication Technology (ICT) Consultant based in Eldoret. He is a member of the Sickle Cell Federation of Kenya (SFK).
- **Ms. Eunice Owino** is a Co- Investigator of the SCDRCP. She is the founder and executive director of the Sickle Cell Uhuru Trust (SCUT) and member of the PEN- PLUS (Package of Essential Non- Communicable Disease interventions) Advocacy voices. She a member of the Board of Directors of the Sickle Cell Federation of Kenya (SFK).

Acknowledgement

- **The Registry Administrators**

Stephen Nalyanya, Absolom Simiyu, Anne Wanyonyi, Joy Watitwa - Bungoma
Henry Kafuna, Anthony Lubuka and Susan Lwande - Busia
Mwanaarabu Risper and Felix Senah - Kakamega
Nancy waliaula - Vihiga
Oscar Wanyonyi, Velma Olunga and Justus Maloba - Trans-Nzoia

Their role in coordinating the SCDRCP activities in the counties, administering and marking the pre-tests and post-tests and collecting the data of the PLWSCD,

- **The County Health Management Team (CHMT) members.**

Their role in providing leadership in Care, Education and Research activities in the counties.

- **The Consultants**

Dr. David Lubanga, Dr. Zacheus Were, Dr. Millicent Wanyama - Bungoma
Dr. Emma Namulala - Busia
Dr. Roselyne Malangachi and Dr. Bonface Nyumbile - Kakamega Dr. Beatrice Shiruli - Vihiga
Dr. Rachel Inginia Kokwo - Trans-Nzoia

Their role in the care of patients and their willingness to take charge of the SCD control activities in the respective counties.

- **The Non-communicable Disease (NCD) coordinators.**

Ms. R Nyangau - Bungoma
Ms. Grace Midambo - Busia
Ms. Rose Muhando - Kakamega.
Mr. Arnold Kihima - Vihiga
Mr, Silas Wambulwa - Trans-Nzoia

Their role in coordinating the registration of PLWSCD and the CME activities.

- **The Health Care Providers (HCP)**

Their role in taking care of the patients, participating in the Pre-test and Post-test assessments and promising to effectively participate in the setting up of SCD registries, specialized clinics and control activities.

- **The PLWSCD and their Care takers.**

Their role in providing the information that was analyzed and used to make generalization in order to provide the recommendations on the way forward in the improvement of Care, Education and Research activities required for the implementation of SCD registries, specialized clinics and control programme.

- **The Data Team.**

Mr. Paul Obwong, Ms. Velma Olunga and Mr. Davis Nalyanya for their role in the data entry and cleaning as well as the preparation of the power point slides for presentations. Mr. Michael Odawa, Maurice Shilabula and Ms. Faith Yego for their role in the data analysis.

- **The Funders.**

The **International Cancer Institute (ICI),** Eldoret which funded the preparation of the data collection tools and the initial visits to counties to inform the County Health Management Teams (CHMT) about the study activities.

The **Research Development Fund (RDF)** of the Department of Child Health and Paediatrics, School of Medicine, College of Health Sciences for funding the field activities (Data collection, the Continuous Medical Education), data entry and analysis, Feedback to the CHMT, writing of the Technical Report and dissemination of the findings.

Special thanks to Mr. James Kipsang Cheruiyot a seasoned resource mobilization consultant who currently serves as the managing director of Holistic Resources International Limited for guiding the team through the process of grant applications.

- **The Sickle Cell Federation of Kenya (SFK).**

The umbrella body whose platform was used by the investigators to carry out the activities. The SFK seeks to support the welfare of PLWSCD within the jurisdiction of Kenya and also aims is to work closely with the Ministry of Health (MOH) and the County Health Management Teams (CHMT) to set the appropriate standards of CARE, EDUCATION and RESEARCH in SCD.

- **The Reviewers.**

Prof.Fabian Esamai, Prof. Samwel Ayaya, Prof. Lameck Diero and Prof. Sherri Bucher for reviewing the work and providing professional guidance in writing the technical report.

References

1. Angastiniotis M, Modell B (1998) Global epidemiology of haemoglobin disorders. Ann NY Acad Sci. 850: 251-269.
2. Grosse SD, Odame I, Atrash HK, Amendah DD, Piel FB, et al. (2011) Sickle cell disease in Africa: A neglected cause of early childhood mortality. AM J prev Med. 41(suppl 4): S398–405.
3. Uyoga S, Macharia AW, Mochamah G, Ndila CM, Nyutu G, et al. (2019) The epidemiology of sickle cell disease in children recruited in infancy in Kilifi, Kenya: a prospective cohort study. Lancet Glob Health. 7(10): e1458–66.
4. Tenge CN (2019) Preventing birth of sicklers as an effective strategy in a sickle cell disease control programme. East African Medical Journal. 96(1): 2241 -2249.
5. Aluoch JR, Aluoch LH (1993) Survey of sickle cell disease in Kenya. Trop Geogr Med. 45(1): 18-21.
6. Kuta ESM, Njuguna FM, Tenge CN, Ganda BOK (2019) Newborn screening for sickle cell disease at Kisumu County hospital, Kenya. East African Medical Journal. 96(2): 2419 - 2429.
7. Watenga EK, Songok JJ, Tenge CN (2019) The Prevalence of Sickle Cell Trait among Adolescents in Bungoma County, Kenya. East African Medical Journal. 96(5): 2683 -2691.
8. Makani J, Ofori-Acquah SF, Nnodu O, Wonkam A, Ohene-Frempong K (2013) Sickle Cell Disease: New Opportunities and Challenges in Africa. The Scientific World Journal. 2013: 1-6.
9. Modell B, World Health Organisation, Hereditary Disease Programme (1994) Guidelines for the Control of Haemoglobin Disorder. World Health Organisation.