

# Cancer Epidemiology and Referral Networks in Western Kenya: A Call for Action

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**Abstract:** *Cancer is the third cause of death in Kenya after infectious disease and in the recent past has drawn a lot of attention due to the exponential increase in both mortality and morbidity and incidences. Cancer is a silent disease with symptoms like other disease conditions that may be mistaken for non-cancer diseases. Therefore, early identification and active referral of cases for cancer management remain important to mitigate severities associated with an extended delay in seeking care. In this secondary analysis, we sought to determine the cancer networks for patients seeking services at the Jaramogi Oginga Odinga Teaching and Referral Hospital (JOTRH). Specifically, this analysis focused on the patient referral network to JOTRH. Data was obtained through a questionnaire and desk review of patient records, analysis done using various statistical packages R and SAS, and graphs and tables using Excel. The World Health Organization (WHO) Cancer classification based on anatomical classification was used. Of the 320 cancer participants enrolled, the majority >30% of the cancer cases were from Kisumu and Siaya counties. Breast, cervix, esophagus, and prostate cancers were most prevalent respectively. More than 60% of patients were in stages II and III at the time of diagnosis. Further, alluding the role of social behavior on the impact of uptake of cancer services amidst the many cancer screening programs in place. This study found that the majority of the patients came from seven counties with more than 60% coming from two Counties of Kisumu and Siaya. There is a need for public health education and follow-up on the need for early cancer screening with referral strategies to realize the impact of cancer screening.*

**Keywords:** Cancer Referral, Cancer, Turnaround time, cancer networks

## 1. Introduction

Cancer is among the leading causes of morbidity and mortality worldwide with an exponential increase in both mortality and incidence over time. Existing statistics indicate that 32.5 million persons are living with cancer and 14.1 are new cancer cases and subsequently, by 2030, the number of new cancer cases will increase to 21.7 million persons (Torre et al., 2016) (Ebrahimi et al., 2019); (Health, 2017). Globally approximately 1 in 6 deaths that occur are associated with cancer and approximately 65% of such deaths occurred in the low- and middle-income countries across the world (Bray, Ferlay, & Soerjomataram, 2018; Ferlay, 2019). Worldwide, the most common cancer is lung cancer which accounts for 13% of all cancer detected, followed by breast cancer at 12%, colorectal cancer 10%, prostate 8%, stomach 7%, liver 5%, cervix 4%, esophagus 3%, bladder 3% and remaining cancer accounted for 35% of all the cases reported worldwide. The most common cancer in men was lung cancer while breast cancer in women (Plummer et al., 2016; 2016; (Bray, Ferlay, & Soerjomataram, 2018).

Cancer is a term used to describe a group of malignant tumors with a common characteristic of uncontrolled growth of abnormal cells that have acquired the capacity to spread and metastasize to distant sites through circulation (NIH, 2014). Cancers are caused by combined genetic and non-genetic changes induced by environmental factors that trigger inappropriate activation or inactivation of specific genes leading to neoplastic transformations, or abnormal cell growth. In developed countries, it is now possible to identify particularly high-risk individuals and potentially design an efficient strategy for cancer referral mechanism and

prevention, yet this still poses a significant challenge in developing countries, especially the sub-Saharan Africa.

Cancer referral networks are key in the entire chain of clinical pathways in ensuring all services needed are received within the health facility or a second opinion is sought on cancer management. Where referral networks are not well defined or the chain of clinical pathways is not complete, patients are bound to be lost to follow-up (G. C. Buckle et al., 2022). Cancer being a progressive disease if diagnosed early can be treated and patients recover fully however, the biggest challenge is getting a referral system that ensures that those identified with potential cancer at the primary healthcare are referred for specialist evaluation to higher health facilities. These mechanisms of referral do not exist and if it does, it is not structured and remains unknown to many. Delays in cancer referral may occur throughout the diagnostic pathways and the time taken to make the clinical decision to make a referral from a primary health care facility and secondary care have not been defined. Identifying patients with cancer poses a lot of challenges even though it remains an important task in medical practice (Salika et al., 2018).

Effective referral systems with traceability of patient's prognosis while on treatment is crucial to the success of cancer interventions. While countries in the Western world ensure efficiency in care and treatment for their cancer patients through an integrated health system Ansar, Adnan et al 2023; the opposite has been reported in the sub-Saharan African region Kenya being one of them; Kisiangani. Cancer referrals from Kenya to other countries have increased exponentially and most of such referrals are done in the quest to seek a second opinion (Kurian et al., 2017). These

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decisions are made when there is an apparent disease that has progressed to worse stages (May Pini et al., 2012), is fragmented and not easily accessible, data untraceable and the magnitude of the cancer problem is not known. The fragmented referral system for cancer patients increases the overall cost of management and unnecessary wastage of resources. Where there is access to treatments, the cost of treatment remains unaffordable to many households (Geynisman et al., 2014). Therefore, strengthening cancer referral systems and follow-ups would ensure efficiency and effectiveness in the management of cancer patients.

In many countries within the sub-Saharan region, cancer referral services are fragmented and not easily accessible due to long waiting lists, cost of diagnostic services, and complexity of initiation on therapy or surgical procedures or data traceable hence the magnitude of the cancer problem is not known. Identifying early-stage cancer and providing the necessary clinical intervention at the right time is the key to improving cancer survival. Screening for early-stage cancer confers high survival benefit, presumably by permitting timely detection of early-stage of cancer disease. For instance, in lung cancer, stage progression is associated with decreased surgical cure rates and poorer overall survival (Farhood et al., 2018; Farhood et al., 2019). In most cases, this delay is associated with an incomplete or fragmented referral system that ensures patients are referred to specialists in the next level of clinical care (Yoo et al., 2018). Referral of -cancer patients for specialist care should guarantee better clinical management and outcome, however, some factors influence the referral chain that would not guarantee the complete chain of custody of the referred patients. These delays in the referral system contribute to the outcome of not being referred for specialized medical care due to challenges in the management, and the timely.

## 2. Methods and Approach

This study was conducted at the Jaramogi Oginga Odinga Teaching and Referral Hospital (JOOTRH) in Kisumu City. This study site is a level six health facility in the country and was selected because is a referral hospital for cancer services in the wider Nyanza and western regions.

Sampling techniques of the purposive method were employed in the selection of potential participants to be enrolled in the study, who were diagnosed with cancer. The technique enabled the researcher to obtain data from a defined period from the cancer registry and also only from the potential respondents that had the kind of information needed, and to cut down on time and other resources that could have been wasted in interviewing people who did not have the required criteria of enrolment. A convenience sampling technique was used in the data abstraction process to pick relevant information from the registries that included dates patients were seen, diagnosis requested, clinical decision made, type of cancer, demography, and the referral data for those who sought services in a different facility or out of the country. This technique was used to save time and to cut down on the cost of the study, secondly, from the sample population used is a representation of a general population since JOOTRH is a referral hospital for more than 6 counties in Western Kenya

with an approximate population of 8 million (30%) of the national population.

### Data Collection and Processing

Quality control /quality assurance was done on data collected that have been abstracted. Individual data collected was entered into an Excel sheet and accuracy and completeness were determined. Data analysis was done using an R statistical package (P, version 16, College Station, Texas, USA). Data entered in Excel was uploaded into the SAS (SAS CORP, version 16, College Station, Texas, USA) software, and quality, accuracy, and completeness were determined. All tools for data collection were stored well and used in verification or clarification.

### Data Management Analysis

Data was managed and analyzed using SAS (SAS, Institute version 16, College Station, Texas, USA) and R package. Descriptive statistics of mean and median were calculated. The median delay was calculated in days. The patient delay was estimated as the median. For comparing the variables, the non-parametric Mann-Whitney U test and Kruskal-Wallis test were done to determine whether there were significant differences between lengths of delay. Participant demographics were summarised using percentages, ordinal, and nominal variables. Data was analyzed using R version 4.3.0. Turnaround time was obtained by calculating the period taken between the time the patient diagnostic request was made and the time diagnosis and clinical decision were determined. To determine the time to diagnosis and clinical decision for patients receiving cancer services at the oncology unit at JOOTRH, Turn Around Time (TAT) was first calculated by subtracting dates between the following time points and results recorded as months; The Level of significance was determined at  $P \leq 0.05$  was considered as statistically significant. Raw data were entered into Microsoft Excel and password protected to ensure access by authorized persons only. Other analysis involved the calculation of descriptive statistics; frequencies, standard deviations, and means and medians. Outputs of statistical analysis were presented in the form of tables, graphs, and charts.

### Ethical Considerations

The approval to conduct the study was given by the Jaramogi Oginga Odinga University of Science and Technology Ethical Review Committee and the School of Graduate Studies. National Commission for Science and Technology (NACOSTI). The Leadership of the Hospital equally provided his approval for the study to be conducted at the Hospital premises.

## 3. Results and Discussion

### Results

#### Baseline Characteristics

Between Jan 2022 to Sept 2022, a total of 322 participants seeking services from the oncology center at the Jaramogi Oginga Odinga Teaching and Referral Hospital were taken through the study consenting process and screened. Out of the 322 screened, 320 met the study eligibility criteria and were consented and enrolled in the study. The baseline characteristics of the study population are presented in **Table**

1. Kisumu and Siaya Counties bore the burden of the cancer patients seeking services at the JOOTRH and this accounted. On clinical characteristics, the average TAT was determined to be 21.2 months. The majority of the participants enrolled were women which accounted for 64% of the total population compared to men who were 36%. The majority of the population was married 81% (259/320) and the difference in men and women who were married was significant (Chi-

square Test:  $P < 0.001$ ). There was also a significant difference in household income (chi-square test:  $p = 0.01$ ) with approximately, 79% (253/320) of the participants having an average monthly income of 10,000Ksh or less. The majority of the participants had a low level of education below primary and highest education at the Primary School level, and they accounted for 70% (223/320) Chi-square Test:  $p = 0.008$ .

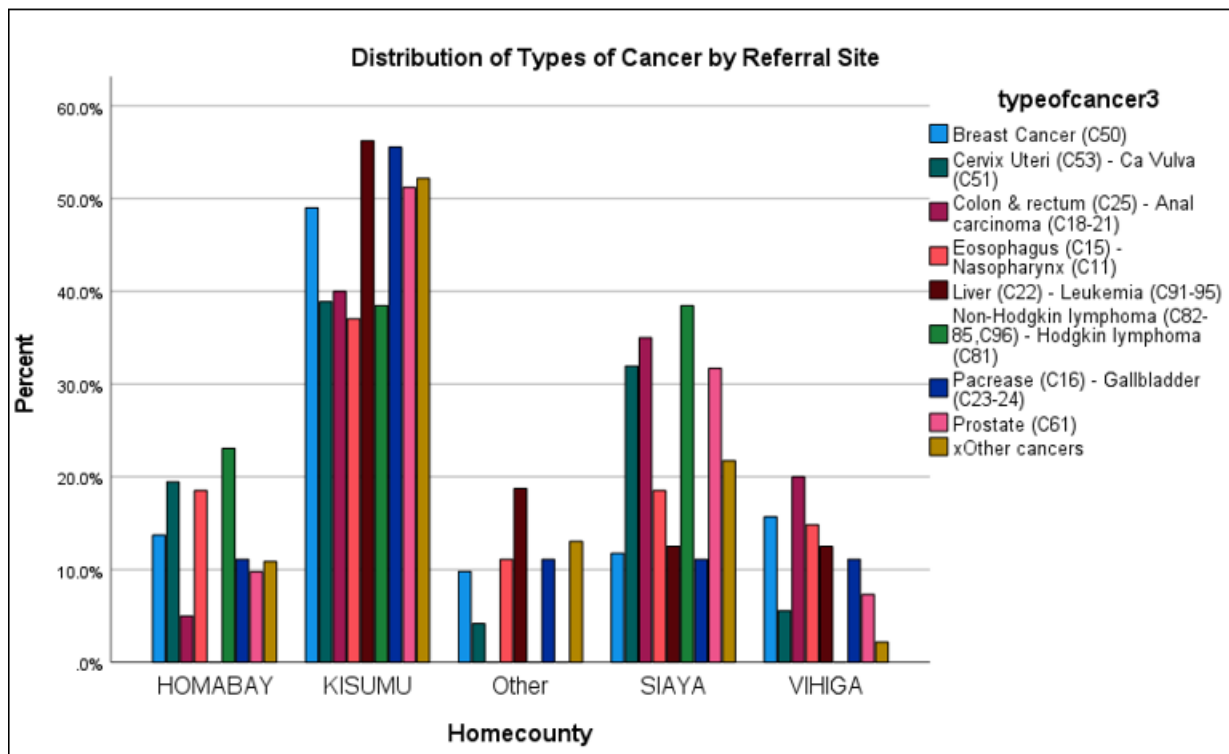
**Table 1:** Baseline Demographic Characteristics of the study Participants in a cohort of cancer patients receiving clinical care at the Jaramogi Oginga Odinga Teaching and Referral Hospital in Kisumu.

Characteristic	Overall, N = 320 <sup>1</sup>	Female, N = 205 <sup>1</sup>	Male, N = 115 <sup>1</sup>	p-value <sup>2</sup>
<b>Overall Turn Around Time (months):</b>	21 (6, 48)	21 (6, 48)	21 (8, 48)	0.92
<b>Home County</b>				0.89
Kisumu	144 (45%)	96 (47%)	48 (42%)	
Siaya	77 (24%)	48 (23%)	29 (25%)	
Homabay	45 (14%)	29 (14%)	16 (14%)	
Vihiga	31 (9.7%)	18 (8.8%)	13 (11%)	
Other	23 (7.2%)	14 (6.8%)	9 (7.8%)	
<b>Occupation</b>				0.65
Farmer	136 (73%)	91 (74%)	45 (%)	
Employed	99 (31%)	62 (30%)	37 (32%)	
Unemployed	85 (27%)	52 (25%)	33 (29%)	
<b>Marital Status</b>				<0.001
Married	259 (81%)	155 (76%)	104 (90%)	
Single	28 (8.8%)	18 (8.8%)	10 (8.7%)	
Widowed	33 (10%)	32 (16%)	1 (0.9%)	
<b>Level of Education</b>				0.008
No education	79 (25%)	49 (24%)	30 (26%)	
Primary	144 (45%)	100 (49%)	44 (38%)	
Secondary	69 (22%)	46 (22%)	23 (20%)	
Tertiary	28 (8.8%)	10 (4.9%)	18 (16%)	
<b>Religion</b>				>0.99
Christianity	313 (98%)	200 (98%)	113 (98%)	
Muslim	7 (2.2%)	5 (2.4%)	2 (1.7%)	
<b>Household Income</b>				0.011
>10,000	67 (21%)	34 (17%)	33 (29%)	
10,000	253 (79%)	171 (83%)	82 (71%)	
<b>Funding Medical Costs</b>				0.67
NHIF	288 (90%)	184 (90%)	104 (90%)	
SELF	14 (4.4%)	8 (3.9%)	6 (5.2%)	
HARAMBEE	18 (5.6%)	13 (6.3%)	5 (4.3%)	

### Distribution of the Cancer Types Prevalence in the Study Population vs. Cancer Referral Sites

Cancer cases at the JOOTRH were mostly from Kisumu and Siaya County which accounted for more than 70% of the cases. Figure 1 demonstrates the most prevalent cancers in this study population were cancer of the cervix/Ca vulva, followed by oesophageal cancer, breast cancer, prostate cancer, and cancer, of cancer the colon. Kisumu County and Siaya bore the burden of cancer in their study population of other groups of cancers. Cancer of the cervix was more

prevalent in Siaya followed by Migori, Kisumu, and Vihiga counties respectively. Leukaemia was more prevalent in Kakamega and Migori counties. Oesophageal cancer was most prevalent in Vihiga, Kakamega, and Kisumu. Cancer of the prostate was most prevalent in Kisii, Siaya, Kisumu, and Vihiga Counties. It is not clear the cancer distribution patterns in Kisii, Busia, and Kericho demonstrated as the numbers of patients referred from these counties were very few and were lumped up as other differential pattern prevalence different from the rest of the counties as seen in Figure 1.



**Figure 1:** Overall Distribution of Cancer Cases by location of the habitat Referral Sites for the Patients Seeking Health Services from and type of cancers in a cohort of cancer patients seeking services at the Oncology Unit Jaramogi Oginga Odinga Teaching and Referral Hospital in Kisumu, Kenya.

**Table 2:** Turnaround Time for Cancer stratified by cancer staging for patients Seeking Services at the Jaramogi Oginga Odinga Teaching and Referral Hospital, in Kisumu

**Table 2:** Analysis of Delay in Cancer Management across the various cancers in a cohort of cancer patients attending cancer care at the Jaramogi Oginga Odinga Teaching and Referral Hospital Laboratory, in Kisumu Kenya.

**Delay in Cancer Management**

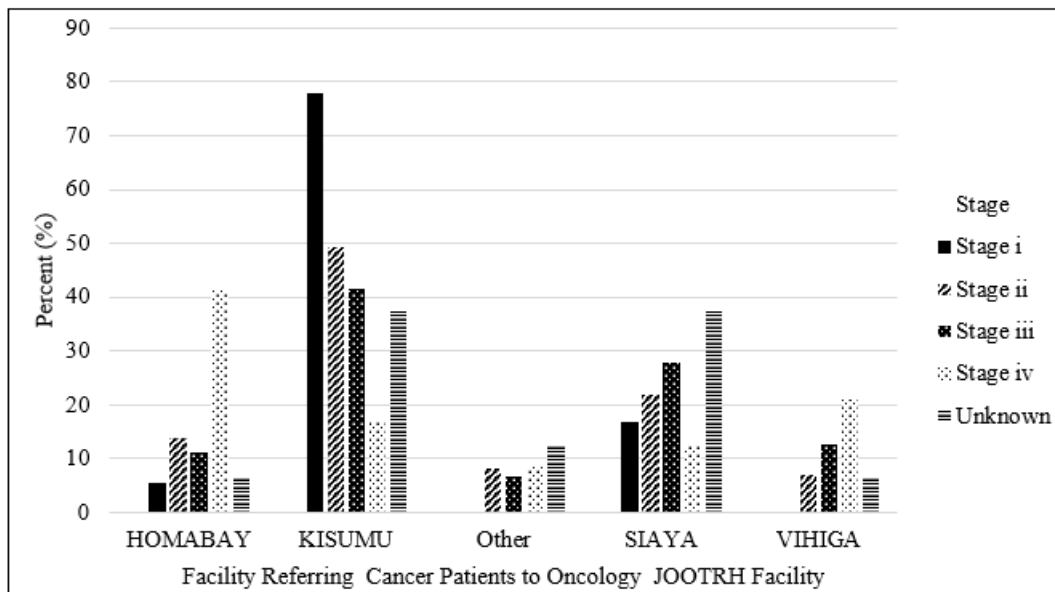
TAT	Overall, N = 320 <sup>1</sup>	Breast Cancer (C50), N = 51 <sup>1</sup>	Cervical (C53) - Ca Vulva (C51), N = 72 <sup>1</sup>	Colon & rectum (C25) - Anal carcinoma (C18-21), N = 20 <sup>1</sup>	Esophagus (C15) - Nasopharynx (C11), N = 53 <sup>1</sup>	Liver (C22) - Leukemia (C91-95), N = 16 <sup>1</sup>	Non-Hodgkin lymphoma (C82-85, C96) - Hodgkin lymphoma (C81), N = 13 <sup>1</sup>	Pancreases (C16) - Gallbladder (C23-24), N = 8 <sup>1</sup>	Prostate (C61), N = 41 <sup>1</sup>	Other cancers, N = 46 <sup>1</sup>	p-value <sup>2</sup>
Turn Around Time (months):	21 (6, 48)	23 (11, 56)	22 (9, 46)	21 (9, 40)	20 (5, 37)	19 (13, 41)	13 (7, 22)	16 (14, 93)	22 (10, 48)	22 (4, 55)	0.056
Onset-Healthcare (months):	15 (2, 40)	17 (5, 47)	16 (2, 38)	16 (8, 36)	14 (1, 35)	17 (10, 29)	9 (2, 18)	10 (2, 91)	17 (4, 35)	14 (1, 54)	0.32
Healthcare-Diagnosis (months):	0.83 (0.13, 8.35)	0.80 (0.12, 7.20)	0.98 (0.19, 11.64)	0.63 (0.16, 6.77)	0.60 (0.17, 5.93)	0.90 (0.27, 10.76)	1.10 (0.25, 4.99)	1.50 (0.12, 10.32)	0.93 (0.20, 5.67)	0.80 (0.04, 12.61)	0.90
Diagnosis-Treatment (months):	2.6 (0.4, 12.7)	2.8 (0.4, 9.2)	2.8 (0.5, 11.5)	2.7 (0.5, 8.6)	2.4 (0.6, 9.0)	1.5 (0.4, 7.0)	2.0 (0.5, 8.7)	2.2 (0.6, 9.7)	3.2 (0.5, 30.8)	3.0 (0.6, 11.4)	0.24
<sup>1</sup> Median (95th - percentile)											
<sup>2</sup> Kruskal-Wallis rank sum test											

**Distribution of the Cancer Staging by the Patients Referral Site.**

Approximately 40% of all the patients who were referred from Homabay were in Stage IV cancer, followed by 22% from Vihiga counties. Of the participants who were enrolled in the study, cancer referral cases with stage III were mostly

from Kisumu and Siaya Counties 40% and 29% respectively. Kisumu County accounted for 78% of the patients who came for cancer services at Stage I. Followed by Siaya at 18% and Homabay counties at 4%. However, it is worrying that a good proportion of participants 5% (16/320) were not staged or records captured in the clinical records for reference.





**Figure 2** The cancer burden based on the Cancer referring and the distribution by type of cancer Patients to the JOOTRH in Kisumu Kenya.

**KEY:** **BLACK** Proportion of patients at Cancer stage I, **Striped black** is the proportion of patients with Cancer stage II, **Dotted black** is the proportion of patients with cancer stage III and the Proportion of cancer in stage IV are **white dotted black** while those with unknown staging are in **Black white horizontal line** respectively.

#### 4. Discussion

Data obtained from the current study shows that the majority of the study participants were female and accounted for sixty-four percent of the study population. Most of the study population were above the midterm age, with a median age of fifty-five years. More than eighty percent of the participants were at cancer stages II and III at the time of referral to the JOOTRH cancer centre. The majority of the participants were married, which is synonymous with many African settings where traditional marriage even without a certificate of marriage is considered legal. Approximately 79% of the patients reported having an average low family income of approximately ten thousand per month, given that most of them were either employed or may have been in casual employment given the low wages reported and they could have delayed seeking services because of financial constraint or other unknown factors as demonstrated in other studies (Tesfaw et al., 2020; Wei et al., 2021). Relatively, ninety percent of the study participants funded their cancer treatment using national insurance schemes procured through NHIF with only a few funding their treatment through out-of-pocket self-funding or family donation. This may have made it easy for most participants to access care even though overall they fall under the low-income cadre. Kisumu County was leading with the highest number of cancer participants who received services from the JOOTRH. This finding was not unusual because JOOTRH is a facility within Kisumu County and may have been the preferred choice for many but also because it's the only cancer treatment center in the Nyanza region.

This study also shows the most prevalent cancer was cervix/Ca uteri (C53/C51) followed by the oesophagus/nasopharynx (C15/C11) breast cancer (C50) prostate (C61) Colon & rectum (C25)/Anal carcinoma (C18-21) at as five major cancers in this population respectively see

Figure 1. This is consistent with the available literature on cancer prevalence in Kenya where cervical and breast cancers are prevalent in women and prostate and oesophageal cancers in men (Wakhisi et al., 2005) et al., 2005; (Kobia et al., 2019); however, the increase in the number of oesophageal/nasopharyngeal cancers in Kenya needs to be investigated. The median duration taken from onset of illness to clinical decision was twenty-one months as shown in Table 2. While delay in cancer management has been reported in many studies (Botey et al., 2021) et al., 2021; Click or tap here to enter text. Somanna et al., 2020; Walpole et al., 2022; Somanna et al., 2020), the current study provides a unique near accurate state of cancer management delays situation in many settings in Kenya with significant delays associated with patients and health facility as seen in the TAT1 and the overall TAT.

A public health action towards the improvement of cancer services uptake must consider those factors that are patient-associated and those that target health system structures with the best approach being health system integration with a focus on primary healthcare. Additionally, to improve the quality of cancer care should integrate cancer screening, diagnosis, and clinical decisions in the routine hospital pathways. Studies conducted in Australia and the United Kingdom have demonstrated cancer management can be effective and efficient through the integration of health services and the provision of funding to support cancer management clinical pathways Diamand (Chapman et al., 2022). The delay between the onset of illness to the first hospital visit was ten times longer than any of the time points with participants who had previously gone for initial screening being less likely to go to the hospital following the onset of illness. These outcomes pose a question of whether early cancer screening translates to increased uptake of cancer services or not or what is the social need that is still unmet on cancer screening and transitioning to care. This may mean that there could be some

social barriers to seeking cancer services that need to be explored (; Mimouni M. et al 2018; Chapman, Emma. J et al 2020; Mimouni et al., 2021; Rendle et al., 2019), Patient related factors that lead to delay in seeking services needs to be investigated, as this may be associated with fear of the unknown or stigma as demonstrated in other studies elsewhere that found negative beliefs about cancer, fear and disregarding symptoms and use of alternative medicine (Adewumi et al., 2022; Olbodun et al., 2022; Wei et al., 2021). In the analysis comparing TAT and type of cancer, there was no statistical significance in the TAT as seen in Table 4.3, however, the delay in cancer management observed was recorded in all cancer types regardless of the cancer and thus lack of statistical significance. In a meta-analysis of peer-of cancer studies, a four-week delay was associated with increased mortality in breast cancer patients and a two-week delay in treatments was associated with disease progression to severity (Unger et al., 2019; Asombang et al., 2019; Basharat et al., 2019) across the various treatment options. Delay in diagnosis (TAT2) The participants with varying cancer stages were mostly less than 1 month while that delay in cancer clinical decision had a median delay of > 2 months and remained a high TAT for cancer patients as this is a progressive condition.

The cancer referral networks were within the five major counties within Kenya, mostly bordering Kisumu County. However, Kisumu County bore the largest cancer burden followed by Siaya, Homabay, and Vihiga counties respectively. More than 40% of the cancer cases were in Kisumu County. In the interview, it was noted that most cancer patients were referred to Jaramogi Oginga Odinga Teaching, and Referral Hospital from five major county referral hospitals namely Siaya, Busia, Kakamega, Vihiga, and Kericho based on the patients enrolled. The JOOTRH was a well-known cancer center and therefore most intra-referrals were within the country and to JOOTRH as opposed to external referrals see Figures 4.1 and 4.2. It's not known, the factors that are driving the differential prevalence of the various cancers in certain regions. However, this would be interesting to conduct further research to determine why cervical cancers were more prevalent in Vihiga, Kakamega Busia, and Kisumu Counties compared to the rest of the referring facilities.

## 5. Conclusion

In conclusion, this study provides important information on the delay in cancer management through the clinical pathways and equally identifies the gaps associated with the lack of public awareness of the need for early cancer screening. To the best of the investigator's knowledge, this is the first study to determine the actual TAT for cancer management of patients in Kenya. While cancer screening is known to help identify cancer cases at early stages, this study demonstrates that going for screening does not equate to uptake of care services for cancer, therefore, there are still gaps in ensuring that those who go for screening (and found to have abnormalities, indicative of cancer), needs to be referred for further check-up or medical attention is sought. These results provided a focus that targets health systems' interaction with patients at the point of entry the need to strengthen screening for cancer at the primary healthcare level and the recently established initiative by the Kenyan government on the use of community health workers to support primary health would come in handy.

## 6. Recommendation

There is a need to develop policies to strengthen cancer awareness of the need for cancer screening and cancer referral as early as the early signs are identified. cancer management and research.

## 7. Suggestions for Future Research

Given the delay in cancer management, from onset to clinical decision, as demonstrated by this. Study, there is a need to initiate efficient and effective operational research studies to evaluate the impact of cancer screening services on cancer services uptake in Kenya.

There is a need for studies to address the social behavioral factors associated with the delay in cancer management to improve cancer screening, diagnosis, and clinical decisions.

Integrated health systems approach.

The Ministry of Health should establish strong policies that guide cancer patients.

Referral networks from low healthcare facilities to cancer management facilities. This will ensure transition patients who go through screening are transitioned to care similar to other programs like

### Authors Contributions

The following investigators contributed to the study design: JAO, SO, LO, BO, RM, and DO. JAO, SO, LO, BO, RM, and DO. The following investigators contributed to the study data collection: JAO, SO, LO, BO, RM, and DO. The following investigators contributed to the planning and/or conduct of manuscript analyses: JAO, SO, LO, BO, RM, and DO. The following investigators contributed to the manuscript preparation and/or revisions: JAO, SO, LO, BO, RM

### Conflict of interest statement

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The members of the writing team declare they have no conflict of interference

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