Title of the Study: The delays in cancer care and the associated causes of the delays in Nairobi, Kenya.

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LIST OF ABBREVIATIONS AND ACRONYMS

LMICs – Low- and Middle-Income Countries

NCDs – Non-communicable Diseases

NMA – Nairobi Metropolitan Area

SSA – Sub Saharan Africa

WHO – World Health Organization

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STRUCTURED SUMMARY

Background: Globally, cancers are among the leading causes of death. In Africa, cancer patients often present at the late stage which has led to poor prognosis. Patients often experience several delays along their cancer care journey. In Kenya, there is also a need to document experiences along the care pathway to identify the gaps and tailor interventions aligned with the government's commitment to improve the experiences and quality of life of patients living with cancer. Therefore, this study aims to better understand delays in the pathway to care and the factors contributing to these delays among patients with selected cancer types in Kenya.

Methods: We will estimate the delays and reasons for the delays among patients diagnosed with breast, colorectum, head and neck, or cervical cancer. Patients will be engaged from the point of treatment. Data will be collected using a semi-structured tool that will be designed first to estimate the duration of delays at each stage and sub-stage of the care pathway, and second examine the factors that may have contributed to the delay.

Expected Outcomes: The findings will provide preliminary evidence to inform policy and decisionmakers in designing and implementing multilevel and holistic approaches to cancer control and improving the overall care pathway. It will also inform subsequent work packages in a programme of work in which this is the first part.

Study Duration: 9 months (November 2024 – July 2025)

1 INTRODUCTION

Cancers are among the leading causes of death worldwide with an estimated 20 million new cases and 9.7 million deaths reported in 2022 [1], which translates to nearly one in six deaths [2]. Globally, female breast cancer and colorectal cancer are among the top five most frequently diagnosed and leading causes of cancer death [1]. In women, breast cancer and cervical cancer are the most diagnosed[1]. Low and middle-income countries (LMICs) have a substantial and growing cancer burden, with a significantly higher cancer mortality than that of high-income countries [1]. In Africa alone, the burden of both non-cancerous and cancerous neoplasms is projected to increase to 2.1 million new cases and 1.4 million deaths by 2040 [3].

Early detection of cancers through early diagnosis reduces mortality an improves quality of life among people who develop a cancer. Yet, the majority of people with cancer in Sub

Saharan Africa (SAA) present in the late-stage (Stage III or IV) thereby contributing to much lower cure rates than could be achieved by giving treatment at an earlier stage [1], [3]–[6]. Screening is also not the answer as most cancers in countries with screening are nevertheless diagnosed based on presentation to a health professional. The WHO attributed the greatest fall in breast cancer deaths in North America preceded screening and adjuvant therapy to earlier diagnosis of symptomatic cases [7], [8]. Therefore, diagnosing and treating common and symptomatic cancers is essential to reducing delays in care, expanding treatment options, and increasing chances of survival.

2 RATIONALE

Patients with cancer often experience delays along the care journey. This late presentation and delay in diagnosis and treatment of cancer has led to poor health outcomes. Several reasons for these delays have been identified, including, the high costs of diagnostic and treatment services; lack of coordination between primary, secondary and tertiary healthcare sectors; inadequate staffing; and continued reliance on traditional healers and complementary medicines [9]. The pathway of care involves multiple levels and interactions between the patient, healthcare provider and the health system, implying that delays may be caused by several factors.

In Africa, presentation and diagnosis of cancer remains low, despite cancer types such as breast, cervical, colorectal, and oral having a high cure rate when detected early and treated according to best practices [10]. For instance, more than two-thirds, that is, 67% [11] and 75% [12]of breast cancer patients, and more than 50% of cervical cancer patients [13] presented at the advanced stages of the disease. With the rising burden of cancer in Africa, it is important to identify the delays along the pathway to treatment and understand the reasons for these delays. Early detection has been shown to be an effective approach in reducing the burden of cancers such as breast, cervical and colorectal cancer [14]. Unfortunately, delays in the care pathway for symptomatic cancers are associated with poorer outcomes, particularly for cancers of the breast, colorectum, head and neck, testes, and for melanoma [4], negatively impacting both mortality rates and quality of life.

3 REVIEW OF LITERATURE

In Kenya, cancer is estimated to be the third leading cause of death and the second leading cause of non-communicable disease (NCD)-related deaths, accounting for about seven percent of the overall national mortality [15]. The most common cancers are cervical, breast

and oesophagus in women, and prostate, Kaposi sarcoma and oesophageal cancers in men [16]. A cross-sectional study conducted at two referral hospitals in Kenya revealed that the three top cancers recorded out of 500 records in the largest national public referral hospital were cervical (62, 12.4%), breast (59, 11.8%), and colorectal (31, 6.2%). [17].

Cancers present at an advanced stage and therefore tend to have poorer outcomes compared to those detected when the cancer was localised [18], [19]. Research has identified significant delays between the initial recognition of symptoms, presentation at a healthcare facility, diagnosis and eventual resolution of care [20], [21], [22]. Various factors contribute to delays at each stage of this process.

In the first stage (recognition of symptoms and presentation to a health facility), delays are often influenced by factors such as the severity or awareness of symptoms, perception of personal risk, and physical or social barriers to accessing care[20], [22], [23], [24]. For example, Forbes et al (2014) revealed that 21% of patients delayed seeking medical attention for over three months [25]. Similarly, studies conducted in Kenya and Nigeria showed that majority of women with breast cancer delayed presenting to a healthcare facility more than three months and over one month respectively [26], [27].

At the second stage (presentation to diagnosis), studies from SSA countries have estimated that delays usually exceed six months [28]. Healthcare providers in Kenya and Tanzania have identified this stage as a critical bottleneck in the care pathway, attributing the delays to several factors. These include failure to recognise/refer patients for symptoms of cancer, weak referral systems, inadequate pathology and laboratory capabilities at lower-tiered facilities, and the cost of diagnostic procedures [29].

The third stage (diagnosis to resolution of care) has been particularly challenging to assess, especially in SSA countries. However, some studies have attempted to estimate the delays at this stage. A longitudinal study done in Uganda showed that the median delay was 33 days in this stage [30]. Similarly, a study done in Pakistan showed a median delay of 28 days [30]. Conversely, a study from Brazil showed that more than 80% of the cancer patients started treatment more than three months after their diagnosis [31]. The cost of treatment was a major factor contributing to these delays [29]. Additionally, patients required multiple visits before receiving a definitive diagnosis or beginning treatment [29], with many diagnoses only being confirmed at tertiary care facilities [16].

Kenya's commitment to addressing key areas in the cancer continuum highlight the importance of this study. Strategies proposed to reduce delays include increasing awareness among patients and providers, expanding access to diagnostic and treatment facilities, and

building the capacity of providers. Additionally, there is a growing need to document experiences along the care pathway to identify the gaps and tailor interventions accordingly. In this study, we will break down the first stage (from bodily change to first presentation to a formal health provider) into the pre-contemplative and contemplative stages. This distinction follows Anderson's observation that individuals may notice symptoms for some time before consciously recognizing their importance [32]. We will also decompose the second stage into delays in referral from primary care to specialist care and delays within specialist care itself. For patients who refer themselves directly to specialist care, we will record subsequent delays, including visits to other providers before diagnosis and treatment. Since some individuals also consult traditional healers after engaging with specialist services [33] we will ask about such visits. Finally, we will estimate delays across four cancer types, that is, breast, colorectum, head and neck, and cervical cancer since these cancers are common cancers that can be cured if treated early and they usually present with symptoms.

This study aims to interview cancer patients to gather accounts of their experiences, quantifying delays and identifying barriers at each stage of their care journey from first symptom to treatment. The study is part of a broader programme of studies to reduce cancer-related delays across Africa funded by NIHR (NIHR158242). This leg of the programme is adapted from a similar study conducted in Nigeria 'Diagnosis of cancer in the south and north of Nigeria: duration and causes of delay'[34] The findings will provide preliminary evidence to inform researchers, policy and decisionmakers in designing and implementing cancer control by reducing delay along the pathway to care.

4 RESEARCH QUESTIONS/HYPOTHESIS

1. What is the estimated duration of delay at stages 1, 2 and 3 of the care pathways.
2. What are the barriers and facilitators that patients encounter at each stage of the care pathway.

5 RESEARCH OBJECTIVES

The overall aim of the study is to better understand delays in the pathway to care and the factors contributing to these delays among patients with selected cancer types in Kenya.

Specific Objectives:

1. Estimate the duration of delay at stages 1, 2 and 3 of the care pathway for curable cancers.

2. Identify the barriers and facilitators that patients encounter at each stage of the care pathway.

6 CONCEPTUAL FRAMEWORK

We will draw from the WHO [35] and Aarhus [36] methods for studies of early cancer diagnosis. These methods are based on retrospective accounts from consecutive consenting patients with specific cancer diagnoses. The WHO guide to early cancer diagnosis [35] defines early diagnosis as the early identification of cancer in patients who have symptoms of the disease. We will explore the patient journey from first noticing bodily changes to the point of resolution where patients receive treatment or referred for palliative care. We will explore the patient journey according to the three stages to diagnosis outlined in the WHO guide to early cancer diagnosis as outlined below [35]:

- Stage 1: awareness of symptoms and accessing care - We will explore symptom appraisal and heath seeking behaviour to the first time they present to a formal healthcare professional. The delay associated with this stage is referred to as 'access delay'.
- Stage 2: Clinical evaluation and diagnosis - We will explore how the patient navigates the health system from first presentation to healthcare professional to receiving a histological diagnosis of cancer and referral for treatment. The delay associated with this stage is referred to as 'diagnostic delay'.
- Stage 3: Access to treatment – from point of diagnosis to resolution (as defined in Table 1). The delay associated with this stage is referred to as 'treatment delay' and includes full investigation to help study the disease and plan treatment.

7 METHODOLOGY

7.1 Study design and population

This is a descriptive study where we will conduct semi-structured interviews with patients to elicit patients accounts of their cancer care pathway. The semi-structured interviews will be designed first to assess delays at each stage and sub-stage of the care pathway (Table 1), and second examine the factors that may have contributed to the delay. The study will focus on patients diagnosed with breast, colorectum, head and neck, or cervical cancer.

Inclusion Criteria

- Patients with a first histological confirmed diagnosis of breast, colorectum, head and neck, or cervical cancer.
- Patients aged 18 years and above.

- Patients referred from the Nairobi Metropolitan Area (NMA)
- Patients capable of providing informed consent.

Exclusion Criteria

- Patients with a diagnosis of a cancer secondary to a primary cancer.
- Any patients who are acutely ill or receiving end of life care.
- Patients with a recurrent cancer.

The number and reasons of the exclusions will be recorded.

Table 1: Representation of stage of delay and potential sub-stages

Stage	Dates elicited	Definition	Sub-stage
Stage 1	Date of noticing first bodily change to date of first presentation to a formal healthcare professional	For the context of this study the healthcare provider may be a number of providers including generalist health care provider in small, medium or large primary care facilities or primary/district hospital outpatient/emergency departments. The date the patient first presents to any of the above is the date of presenting to healthcare provider. It does not include dispensaries, community health workers or traditional/faith healers.	Pre-contemplative stage Contemplative stage
Stage 2	Date of first presentation to formal healthcare professional to date of diagnosis	The date of histological confirmation of the cancer. This can be any of the below in order of preference i. Date the specimen was taken ii. Date specimen received by pathologist These proxy dates are informed by the European Network of Cancer Registries Hierarchy for defining the date of diagnosis [35]. However, as the patient may not know the dates in i) and ii) above, we will record the date the patient was informed of the diagnosis as the relevant date, since it is at this point that the clock to treatment starts.	Patients may make >1 visit. We will record all visits to primary care before accessing specialist care covering visits to different and the same specialist service. They may also visit traditional healers in between.
Stage 3	Date of diagnosis to date of resolution	The point of resolution is where the patient either receives first line treatment (surgery/radiotherapy) or the decision that the cancer is too advanced to cure. We will therefore conduct our interview at an appropriate time after diagnosis.	

7.2 Study setting

The study will be conducted within the NMA which comprises Nairobi, and the surrounding counties Kajiado, Kiambu, and Machakos. Nairobi is the capital city of Kenya and is the core for national, regional and international development. As the hub for many healthcare, cultural amenities and recreational facilities, its influences have spread to the surrounding counties. The NMA will enable us to sample patients with diverse socio-cultural and economic backgrounds and healthcare needs.

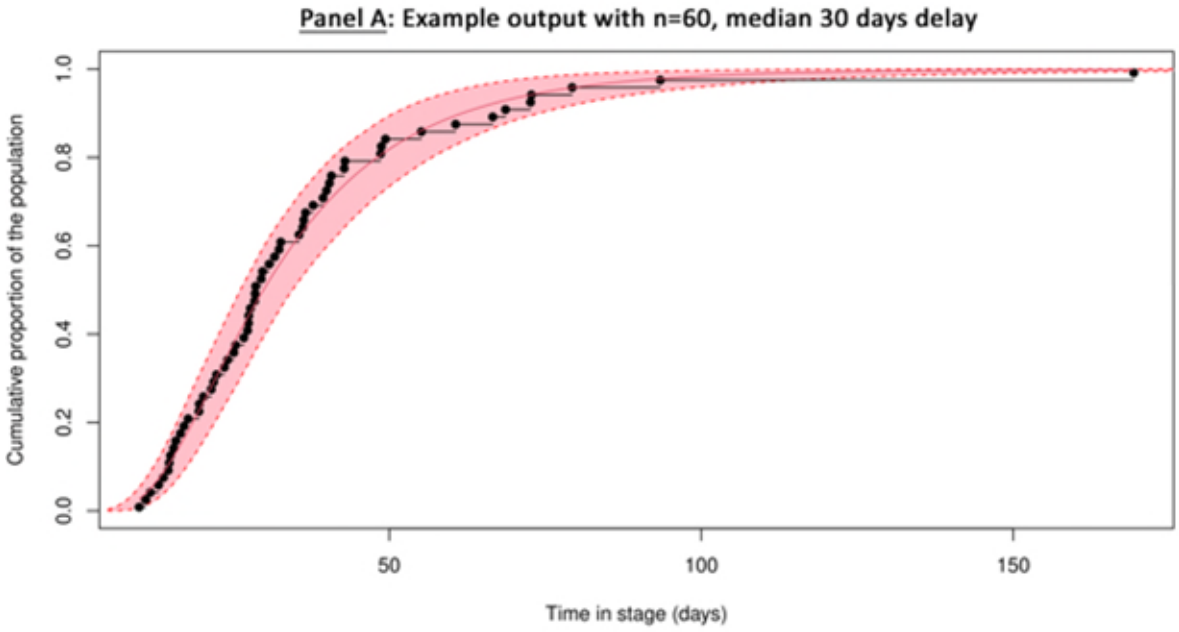
7.3 Sampling approach and sample size determination

A total of 160 – 200 patients will be selected, that is, 40 - 50 consecutive people per selected cancer (cancers of the breast, colorectum, head and neck, cervix). We have selected these four cancers as they have the potential of being diagnosed early and they are the most common cancers where the difference in outcome by stage of diagnosis is large. Moreover, whereas previous studies have focused on one or two cancers, it is more cost-effective to combine different cancers in a single study.

Our sample size calculations are based around the precision with which we can estimate quantiles of the delay (median, 75th, or 90th percentiles) for any group (cancer type). We use a median of 30 days for our example below (Figure 3). A sample of 40 - 50 individuals will mean we will be able to estimate the median delay to a precision of approximately +/- 5 days (95% confidence interval), and the 75th and 90th percentiles to +/- and 12 days, respectively. The confidence intervals will be narrower for results pooled across cancers.

We will not compare sub-groups (of cancers, areas of care or providers) by means of hypothesis tests, since our aim is not to identify differences between sub-groups, but rather to identify headroom for improvement. For example, patients with one type of cancer might be treated more quickly than patients with another type of cancer but still wait too long; or a doctor may make too few appropriate referrals despite making more such referrals than another type of clinician.

Figure 3. Example estimation of median delay



7.4 Study Participants Recruitment

We will recruit consecutive patients from the Kenyatta National Hospital (KNH) until the target number of participants is met for each cancer. KNH is the oldest public tertiary referral facility and caters to cancer patients from all over the country, but we will recruit patients from the Nairobi County and surrounding areas as stated above. The recruitment strategy has been designed so that the treatment pathway is not perturbed.

A clinician/nurse from the treatment team will assist in recruiting patients who meet the eligibility criteria. The clinician/nurse will identify the patients and ask them whether they would be interested in participating in a study to understand their journey with cancer from the point of diagnosis to resolution. The clinician/nurse will also seek permission from the patient for their contact information to be shared with the research team. A member of the research team will then contact patients and arrange for a convenient time to discuss more about the study. The study will be described and if the patient is willing, then signed consent will be obtained.

7.5 Data Collection Methods

7.5.1 Study Instruments

A semi-structured study instrument has been developed to measure delays at each stage of the patient pathway and to elicit the reasons for delay at each stage based on the standard pathway methodology [36],[37]. The questions are intended to elicit information on each stage of the WHO steps to early cancer diagnosis pathway. We have adapted the tool previously used in Nigeria to the Kenyan setting [34].

The interviews will explicate the pathway for each person (people may make multiple attempts to access care and use alternative / traditional pathways) and identify the duration of each stage of the pathway (one to three as per the conceptual framework). The timepoints of interest are detailed in Table 1.

i. *Measurement of delay* -We now describe the steps we will take to get to the best estimate of the dates signifying the end of one stage and the beginning of the next. We will use calendar methodology [38] which proved suitable in our above Nigerian study. We will use annotate a calendar with key time points such as Easter, Christmas, New year, Ramadan, elections and s festivals that may stimulate recall. The interviewing researchers will be taught to ensure trustworthiness of the data by checking back the sequence and time points with interviewees and exploring any inconsistencies. By recruiting patients as close as possible to the point of treatment we will reduce the risk of recall bias. We will tease apart, as much as possible, the gap between first noticing a body change and recognising that this might be a serious indication of disease (pre-contemplative stage), and the subsequent gap between realising the change may be important and reaching an allopathic practitioner. Eliciting the duration of delay by stage will be further facilitated by reference to dates in their personal lives. From the dates we will calculate median delays and, as recommended by WHO [35], the 75th and 90th centiles and relate these to the WHO reference standard of 90 days from symptom to treatment.

ii. *Factors affecting access* - We shall identify causes of delayed presentation that are specific to a particular context and those that are shared. The role of other community members (example health workers, traditional healers) will be explored to try and understand the thought process. We will also elicit views about prognosis, therapy, effectiveness of therapy and local providers (e.g. quality, attitude). Important findings gleaned from accounts of patients' experiences include the attitude of staff and the perception of the quality of the service which would propel interventions that would have benefit for all cancer patients and those with other conditions. We shall elicit the patient's perspective regarding the reasons for any delay and what could be done about it.

7.5.2 Recruitment of Research Assistants

Field interviewers will be selected based on level of education, prior experience working on similar studies and ability to understand and speak English and Kiswahili. The recruitment will follow a transparent process consistent with high ethical and APHRC standards and policies.

7.5.3 Training of research team and piloting of instruments

All data collection and research teams involved in the study will participate in a 5-day training workshop prior to the piloting and data collection activities. The training will consist of detailed sessions on the study objectives, study tools, data collection techniques and ethical considerations. The training will comprise: 1) facilitated sessions on the overview of the study and the work package, the overall aims of the study, the study tools, research ethics, and key sessions on understanding stages on the pathways including time points, the use of the calendar tool as an aid, and a discussion of the topic guide; and 2) mock interviews and role plays. All participants will be required to attend all training sessions and must go through all questions including the pilot and debrief exercise. The study team leaders and field coordinators will receive additional training in the management of data collection; team dynamics, planning and logistics, observing interviews, and spot checking for data quality. The training course will be facilitated by researchers with vast research and field work experience drawn from APHRC, and other collaborating institutions. We will develop training and data collection manuals that will guide both the facilitators and data collectors during the training and data collection process.

Before a data collection starts, pilot testing of all study tools will be conducted. The aims are to 1) test and evaluate the design of the instruments 2) evaluate the feasibility of the study in local settings 3) affirm the validity and reliability of the instruments and 4) familiarise the data collectors with the data collection instruments and procedures.

7.5.4 Data collection procedures in the field

Once the interviewers are recruited and trained, they will be dispatched to the study site as a team. The team will be led by an experienced field coordinator who will oversee coordinating and verifying the quality of the work done by the interviewers. The data collection process will be supervised closely by APHRC research staff.

Prior to conducting an interview, informed consent will be obtained from all participants. Interviews will be conducted with cancer patients who meet the eligibility criteria. Once the

patient indicates that they are willing to participate in the study, and consent has been obtained, the field interviewer will schedule the interview to take place at a time and location that will be agreed upon. The hospital will also provide rooms where interviews can be conducted. Field interviewers will ensure that the location allows for privacy and is quiet. Interviewers will be advised to end the interview if privacy is not able to be maintained. If a participant becomes distressed during the interview, interviewers will also be advised to take a break or stop the interview completely and the participant will be directed to appropriate local support where necessary. Interviewees will be encouraged to have a friend/family member with them as this worked well in the previous study [34]. The discussions are expected to last approximately one hour and sessions will be audio recorded using a digital recorder. Where respondents do not wish to be recorded, we will take comprehensive field notes. In addition to the interview guide, the field interviewer will use a patient description form to collect additional information on socio-demographic characteristics such as age, ethnicity and education level.

7.5.5 Management of data quality during field work

Field interviewers will conduct data collection activities under the supervision of experienced researchers. The research team will conduct sit-ins on a sample of interviews to ensure that the interviewer is asking questions in line with the guide. Permission will be sought from the participant prior to a sit-in being conducted. A sample of transcripts will also be reviewed and verified.

8 ETHICAL CONSIDERATIONS

The protocol and data collection instruments will be sought from the APHRC internal scientific ethics review committee and the Kenyatta National Hospital -University of Nairobi Ethics Review Committee (KNH-UoN ERC). A research permit will be sought from Kenya's National Commission for Science, Technology and Innovation (NACOSTI).

Informed consent will be sought from all participants and permission will be sought from the clinician/nurse who engages with the patient. With the consent process, prospective study participants will be provided with information about the objectives of study, the procedures for participation, the right to abstain from participation in the study or to withdraw consent to participate at any time without reprisals. Participants will also be provided with information about the anticipated benefits and potential risks of the study and measures to ensure confidentiality of information provided. The project will establish safeguards and protections

for potential risks of privacy and confidentiality and possible distress caused by asking sensitive information. Field interviewers will be trained on ethical issues to ensure that guidance on ethical conduct is clearly understood and implemented. Training sessions (above) will cover the ethics of research confidentiality. Some of the questions asked in the survey might bring up certain feelings or make participants feel uncomfortable. Therefore, interviewers will be trained on how to respond to such situations and refer participants who require counselling services to the appropriate programs around their area.

9 DATA MANAGEMENT, PROCESSING AND ANALYSIS

9.1 Data Management and Processing

An electronic version of the semi-structured tool will be programmed onto the Survey CTO platform for data collection. Data will be collected simultaneously using tablets and audio-recorders. The data collected on the tablets will be transmitted to APHRC's online secure servers for storage. The internet will be used to upload the data via internet bundles loaded onto the tablets. Backup of the data will remain on the tablets until the end of field activities. Data transmitted to the central servers will be password protected to allow access to only authorised users. All identifiers (name, identity numbers, phone numbers and places of residence) collected during data collection or for recruitment procedures will be removed from analytical datasets before any data is shared or used in analysis and replaced with unique identifiers. The raw data will be cleaned and transformed as needed for the statistical analysis. This process will involve checking for missing values, outliers, and any data inconsistencies. With the clean data, we shall produce detailed reports with completed tables on different variables as well a more condensed summary of results report. The data collected on the audio-recorders, will be uploaded onto a secure drive accessible only to the research team and re-labelled with a unique study identifier. A unique code will be used to link the audio-recordings and data submitted on the server. After the end of each interview field teams will be required to debrief on the interview to ensure all questions were asked and document any challenges or interesting themes that arose during the interview. All study participants will be assigned unique study identifiers. Audio-taped interviews and records will also be labelled with unique study identifiers. All recorded interviews will be transcribed verbatim in English, saved in MS word format, and quality assured by senior researchers.

9.2 Data Analysis

All interviews will be collected using a tablet and audio-recorded (unless the patient does not wish to be recorded), anonymised as far as practicable, and transcribed verbatim. Interviews that are conducted in Kiswahili language will be translated into English.

As the interviews are semi-structured, the closed-ended questions will be analysed quantitatively and the open-ended questions analysed qualitatively. The closed-ended questions will be used to analyse the stages of delay (Table 1) by computing the duration of delay (median, interquartile range and 90th centile) in months. For instance, stage 2 delays will be computed by calculating the interquartile range from the date when the participant first presented to a formal healthcare professional to the date they received their diagnosis. The mean delay will then be computed for each cancer type. For the open-ended questions, the data will be analysed using framework analysis [39]. Two researchers will read the same set of interviews for each cancer to identify emerging themes and together develop a thematic framework for coding the interviews. All interviews will then be coded according to the thematic framework, aided by NVivo software. Interpretation will be by discussion and consensus between the study team. Data analysis will be iterative, occurring as data collection progresses. We will identity themes within each of the three stages to early diagnosis for each cancer, identify the most important delays that impact on time to accessing treatment, and evaluate the reasons for the delays.

10 STAKEHOLDER ENGAGEMENT AND DISSEMINATION PLAN

We will have a series of structured engagements with various stakeholders including policy makers/decision-makers, community representatives (e.g. civil society organisations) and patient groups (e.g. support groups). We have had one engagement prior to the start of the study to validate the tools and provide insights into the most effective participant recruitment strategy. We will hold another meeting towards the end of the study to discuss the implications of the findings and co-design solutions. Through these engagements, we will also sensitize key persons on the study. We will also seek to present preliminary findings to the stakeholders groups before disseminating to the wider community members, to garner initial reactions to the findings.

Results from this study will be shared in a with stakeholders including the patients with cancer, government representatives from the Ministry of Health (county and national), and professional associations. The findings will also be shared through written reports and publications.

11 STUDY LIMITATIONS AND RISKS, AND MITIGATION OF THE RISKS

11.1 Study Limitations and Mitigation measures

The two main limitation in this study is the sensitivity of interviewing patients within a facility and the potential selection bias. For the latter, we acknowledge that the hospital is very specialised and treats complex patients referred specifically to the institution. Therefore, we do not include patients referred from far afield who would be atypical. We will address this by confining our sample to the NMA therefore, tapping into the distribution across the generality of people living in a populated area. The hospital also has an internal patient navigation support program in operation. This leaves undisturbed the (often circuitous) route patients follow to reach the hospital where they are treated, therefore, the navigation system means that we may under-estimate delay in the destination hospital. To address this, we will endeavour to capture patients at the point of first contact as much as possible. For the former, some patients may be tired or distracted and therefore not willing to participate. As stated, interviews will take place in a private space. In addition to this, interviewers can schedule interviews on non-clinic days in which case transport will be reimbursed.

11.2 Risks and mitigation measures

At a wider level, a risk associated with the study is the current political and economic climate in Kenya which may disrupt care e.g. making it difficult to reach the care facility or health worker strikes. To mitigate against such risks the team will explore the use of real time security reports that reveal any anticipated disruptions in the study sites and plan for data collection on conducive days. Additionally, increase in the current Monkey Pox (Mpox) cases might cause disruptions in care. The team will rely on regular updates from the Ministry of Health and adhere to current preventive measures.

12 MANAGEMENT AND ORGANISATION OF THE STUDY

12.1 Team members/roles

1. **Dr. Shukri Mohamed** is an associate Research Scientist in Chronic Disease Management unit and supports the Kenya National Cancer Strategy. She is a public health specialist with experience and expertise in project planning and management, project implementation, data quality assurance, data analysis and scientific writing. She also has four years of clinical pharmacy practice experience.

Role on the project: Principal Investigator and project manager, will oversee the overall coordination of the project including the research activities, dissemination and policy engagement and reporting.

2. **Dr. Gershim Asiki** is a Senior Research Scientist who currently leads the Chronic Disease Management unit and is a member of the inter-agency NCD technical working group Kenya Ministry of Health.
   Role on the project: Co Investigator, will provide technical guidance on the research design and implementation of the study.
3. Dr. Calistus Wilunda is an associate research scientist and public health practitioner. He has a background in cancer epidemiology and conducting research on large-scale NCD studies.
   Role on the project: Co-Investigator, will charge support the implementation and contribute to dissemination, policy engagement and reporting.
4. Lyagamula Kisia is a public health researcher with over five years of experience in project coordination and stakeholder engagements.
   Role on the project: Co-Investigator, she will oversee the day to day running of the project.
5. Caroline Nyongesa is a medical doctor with over ten years of experience in cancer research.
   Role on the project: Co-Investigator, she will provide technical guidance on the recruitment and engagement of participants.
6. Richard Lilford is a medical doctor with over forty years of experience in Public Health.
   Role in the Project: Co-Investigator, he will provide overall technical guidance to the study design and implementation.

12.2 Timelines of activities

The study will be implemented over 6 months from November 2024 to April 2025. The three initial months will be spent on planning and preparation of the protocol and tools for ethical review and approval. Data collection will be done between February and May 2024. Specific deliverables and timelines are indicated in the Gantt chart below.

Table 2: Timelines of Activities

	2024					**2025**			
	Aug	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**

Stakeholder engagements									
Ethics application									
Recruitment of field researchers									
Training									
Patient recruitment and interviews									
Transcription, checking, coding									
Data analysis									
Report writing and dissemination									

12.3 Budget and Justification of the budget

The budget for the study has been costed at: 20,000 USD (approx. 2,775,045 KES)

Activity	Total (USD)	Total (KES)
Personnel	12,000	1,652,000
Project costs	7,000	990,900
Total direct costs	19,000	2,642,900
Indirect costs	1,000	132,145
Total project costs	20,000	2,775,045

Justification of the budget

The budget is based on the current estimates of prices and wages and includes personnel costs, dissemination, research costs and estimated institutional administrative overheads (indirect costs) which have been calculated at 5% of the total project costs. The overall research costs (7,000 USD) will include: Ethical Review Board Clearance, NACOSTI clearance, Training Materials, Pilot data collection tools, Data collectors communication allowance including airtime for data synchronization and mobilization of participants, Training materials, Pilot Study, and Participants transport reimbursement.

7. APPENDICES

7.1. References

[1] F. Bray Bsc *et al.*, "Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries," *CA Cancer J Clin*, vol. 74, no. 3, pp. 229–263, May 2024, doi: 10.3322/CAAC.21834.

[2] J. Ferlay *et al.*, "Cancer statistics for the year 2020: An overview," *Int J Cancer*, vol. 149, no. 4, pp. 778–789, Aug. 2021, doi: 10.1002/IJC.33588.

[3] R. Sharma *et al.*, "Mapping Cancer in Africa: A Comprehensive and Comparable Characterization of 34 Cancer Types Using Estimates From GLOBOCAN 2020," *Front Public Health*, vol. 10, p. 839835, Apr. 2022, doi: 10.3389/FPUBH.2022.839835/BIBTEX.

[4] R. D. Neal *et al.*, "Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? Systematic review," *Br J Cancer*, vol. 112 Suppl 1, no. Suppl 1, pp. S92–S107, 2015, doi: 10.1038/BJC.2015.48.

[5] W. Hamilton, F. M. Walter, G. Rubin, and R. D. Neal, "Improving early diagnosis of symptomatic cancer," *Nat Rev Clin Oncol*, vol. 13, no. 12, pp. 740–749, Dec. 2016, doi: 10.1038/NRCLINONC.2016.109.

[6] E. Jedy-Agba, V. McCormack, C. Adebamowo, and I. dos-Santos-Silva, "Stage at diagnosis of breast cancer in sub-Saharan Africa: a systematic review and meta-analysis," *Lancet Glob Health*, vol. 4, no. 12, pp. e923–e935, Dec. 2016, doi: 10.1016/S2214-109X(16)30259-5.

[7] I. Jatoi and A. B. Miller, "Why is breast-cancer mortality declining?," *Lancet Oncology*, vol. 4, no. 4, pp. 251–254, Apr. 2003, doi: 10.1016/S1470-2045(03)01037-4.

[8] "GUIDE TO CANCER EARLY DIAGNOSIS," 2017, Accessed: Sep. 09, 2024. [Online]. Available: http://apps.who.int/bookorders.

[9] D. C. Lombe *et al.*, "Original research: Delays in seeking, reaching and access to quality cancer care in sub-Saharan Africa: a systematic review," *BMJ Open*, vol. 13, no. 4, p. 67715, Apr. 2023, doi: 10.1136/BMJOPEN-2022-067715.

[10] World Health Organisation, "Cancer | WHO | Regional Office for Africa." Accessed: Aug. 14, 2024. [Online]. Available: https://www.afro.who.int/health-topics/cancer

[11] P. A. Adeoye, "Epidemiology of Breast Cancer in Sub-Saharan Africa," *Breast Cancer Updates*, Jan. 2023, doi: 10.5772/INTECHOPEN.109361.

[12] E. Jedy-Agba, V. McCormack, C. Adebamowo, and I. dos-Santos-Silva, "Stage at diagnosis of breast cancer in sub-Saharan Africa: a systematic review and meta-analysis," *Lancet Glob Health*, vol. 4, no. 12, pp. e923–e935, Dec. 2016, doi: 10.1016/S2214-109X(16)30259-5.

[13] H. Mimouni *et al.*, "The Care Pathway Delays of Cervical Cancer Patient in Morocco," *Obstet Gynecol Int*, vol. 2020, 2020, doi: 10.1155/2020/8796570.

[14] World Health Organisation, "GUIDE TO CANCER EARLY DIAGNOSIS," 2017, Accessed: Aug. 26, 2024. [Online]. Available: http://apps.who.int/bookorders.

[15] Kenya Ministry of Health, "KENYA NATIONAL CANCER CONTROL STRATEGY," 2017.

[16] T. Martins, S. W. D. Merriel, and W. Hamilton, "Routes to diagnosis of symptomatic cancer in sub-Saharan Africa: systematic review," *BMJ Open*, vol. 10, no. 11, p. e038605, Nov. 2020, doi: 10.1136/BMJOPEN-2020-038605.

[17] L. W. Macharia, M. W. Mureithi, and O. Anzala, "Cancer in Kenya: types and infection-attributable. Data from the adult population of two National referral hospitals (2008-2012)," *AAS Open Res*, vol. 1, p. 25, Nov. 2018, doi: 10.12688/AASOPENRES.12910.5.

[18] R. Etzioni *et al.*, "The case for early detection," *Nat Rev Cancer*, vol. 3, no. 4, pp. 243–252, 2003, doi: 10.1038/NRC1041.

[19] B. Levin *et al.*, "Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology," *CA Cancer J Clin*, vol. 58, no. 3, pp. 130–160, May 2008, doi: 10.3322/CA.2007.0018.

[20] C. Espina, F. McKenzie, and I. dos-Santos-Silva, "Delayed presentation and diagnosis of breast cancer in African women: a systematic review," *Ann Epidemiol*, vol. 27, no. 10, pp. 659-671.e7, Oct. 2017, doi: 10.1016/J.ANNEPIDEM.2017.09.007.

[21] O. Agodirin *et al.*, "Presentation intervals and the impact of delay on breast cancer progression in a black African population," *BMC Public Health*, vol. 20, no. 1, Jun. 2020, doi: 10.1186/S12889-020-09074-W.

[22] B. L. Andersen and J. T. Cacioppo, "Delay in seeking a cancer diagnosis: delay stages and psychophysiological comparison processes," *Br J Soc Psychol*, vol. 34 (Pt 1), pp. 33–52, 1995, doi: 10.1111/J.2044-8309.1995.TB01047.X.

[23] A. J. Ramirez, A. M. Westcombe, C. C. Burgess, S. Sutton, P. Littlejohns, and M. A. Richards, "Factors predicting delayed presentation of symptomatic breast cancer: A systematic review," *Lancet*, vol. 353, no. 9159, pp. 1127–1131, Apr. 1999, doi: 10.1016/S0140-6736(99)02142-X.

[24] L. J. L. Forbes, F. Warburton, M. A. Richards, and A. J. Ramirez, "Risk factors for delay in symptomatic presentation: a survey of cancer patients," *Br J Cancer*, vol. 111, no. 3, pp. 581–588, Jul. 2014, doi: 10.1038/BJC.2014.304.

[25] L. J. L. Forbes, F. Warburton, M. A. Richards, and A. J. Ramirez, “Risk factors for delay in symptomatic presentation: a survey of cancer patients,” *Br J Cancer*, vol. 111, no. 3, pp. 581–588, Jul. 2014, doi: 10.1038/BJC.2014.304.

[26] L. Pruitt *et al.*, “Social barriers to diagnosis and treatment of breast cancer in patients presenting at a teaching hospital in Ibadan, Nigeria,” *Glob Public Health*, vol. 10, no. 3, pp. 331–344, Mar. 2015, doi: 10.1080/17441692.2014.974649.

[27] E. S. Otieno, J. N. Micheni, S. K. Kimende, and K. K. Mutai, “Delayed presentation of breast cancer patients,” *East Afr Med J*, vol. 87, no. 4, pp. 147–150, Apr. 2010, doi: 10.4314/EAMJ.V87I4.62410.

[28] C. Espina, F. McKenzie, and I. dos-Santos-Silva, “Delayed presentation and diagnosis of breast cancer in African women: a systematic review,” *Ann Epidemiol*, vol. 27, no. 10, pp. 659-671.e7, Oct. 2017, doi: 10.1016/J.ANNEPIDEM.2017.09.007.

[29] C. Cross, S. Mokua, R. Ngilangwa, C. Santos, T. Ngoma, and P. G. M. Mujinja, “Beyond ‘Late Presentation’: Explaining Delayed Cancer Diagnosis in East Africa,” *International Political Economy Series*, vol. Part F2092, pp. 93–111, 2024, doi: 10.1007/978-3-031-44123-3_5.

[30] S. Kibudde *et al.*, “Turnaround time and barriers to treatment of newly diagnosed cancer in Uganda: a mixed-methods longitudinal study,” *Afr Health Sci*, vol. 22, no. 1, p. 327, 2022, doi: 10.4314/AHS.V22I1.40.

[31] Â. F. Barros, G. Uemura, and J. L. S. de Macedo, “Tempo para acesso ao tratamento do câncer de mama no Distrito Federal, Brasil Central,” *Revista Brasileira de Ginecologia e Obstetrícia*, vol. 35, no. 10, pp. 458–463, 2013, doi: 10.1590/S0100-72032013001000006.

[32] B. L. Andersen and J. T. Cacioppo, “Delay in seeking a cancer diagnosis: delay stages and psychophysiological comparison processes,” *Br J Soc Psychol*, vol. 34 (Pt 1), pp. 33–52, 1995, doi: 10.1111/J.2044-8309.1995.TB01047.X.

[33] F. S. Makene *et al.*, “Patients’ pathways to cancer care in Tanzania: documenting and addressing social inequalities in reaching a cancer diagnosis,” *BMC Health Serv Res*, vol. 22, no. 1, pp. 1–13, Dec. 2022, doi: 10.1186/S12913-021-07438-5/TABLES/11.

[34] I. J. Fayehun OA, Apenteng PN, Umar UA, Adebayo KO, Owoaje E, Sartori J, Popoola O, Nnabuife U, Oladejo A, Odubanjo O, Ayandipo O, Odukogbe A, Irabor D, A. Muhammad AB, Haruna I, Ajiya A, Suleiman AR, Muhammad ID, Adamou, U. NG, Muhammad S, Tijjani I, Nagwamutse TN, Abdullahi SU, Shittu L, Ado KA, and L. R. AA, Bello AS, Yakasai IA, Omigbodun AO, “Diagnosis of cancer in the south and north of Nigeria: duration and causes of delay”.

[35] World Health Organisation, “GUIDE TO CANCER EARLY DIAGNOSIS,” 2017.

[36] D. Weller *et al.*, “The Aarhus statement: improving design and reporting of studies on early cancer diagnosis,” *Br J Cancer*, vol. 106, no. 7, p. 1262, Mar. 2012, doi: 10.1038/BJC.2012.68.

[37] D. Coxon *et al.*, “The Aarhus statement on cancer diagnostic research: Turning recommendations into new survey instruments,” *BMC Health Serv Res*, vol. 18, no. 1, pp. 1–9, Sep. 2018, doi: 10.1186/S12913-018-3476-0/TABLES/2.

[38] T. Glasner and W. Van Der Vaart, “Applications of calendar instruments in social surveys: a review,” *Qual Quant*, vol. 43, no. 3, pp. 333–349, 2009, doi: 10.1007/S11135-007-9129-8.

[39] J. Ritchie and L. Spencer, “Qualitative data analysis for applied policy research,” *Analyzing qualitative data*, pp. 173–194, Feb. 2010, doi: 10.4324/9780203413081_CHAPTER_9.

7.2. Study Tools

13 Appendix 1: Semi-Structured Tool

SECTION 1: SOCIO-DEMOGRAPHIC CHARACTERISTICS

Age: ☐ Gender: ☐ Occupation: ☐

County of Residence: ☐

Are you married: YES ☐ NO ☐

Highest education: No Formal ☐ Primary ☐ Secondary ☐ Tertiary ☐

Currently working (If unsure, worked in the last week)? YES ☐ NO ☐

Type of Cancer: ☐

How do you plan to pay for your healthcare?

Self ☐ Family & Friends ☐ Health Insurance ☐ All of the above ☐ Not sure ☐

SECTION 2: PATIENTS' ACCOUNTS OF THEIR JOURNEY FROM FIRST NOTICING SYMPTOMS TO TREATMENT

Determination of duration of delays: Several questions start with 'when' and appear in boxes, these will be used to time delays at different stages. The format is based on a series of prompts using a calendar method covering whether it was within the last year, asking participants to relate it to events personal e.g. weddings and in the external world e.g. Christmas etc to assemble a state of points. Unless the patient remembers the exact date, we will record the Monday of the week that conforms to their best estimate. If later, questions help the participant recall certain dates then responses can be revised to reflect that.

Stage 1: Awareness and accessing care

In this section, we will ask you questions to determine the duration of the delays you encountered and the reason behind these delays from when you first noticed a change in your body to when you first visited a formal health care professional because of the change you noticed.

1. Looking back what was the very first (bodily change) you noticed?
    a. Blood in stool, diarrhoea and other changes in bowel habits (Colorectal)
    b. Breast lump, discharge and/or tenderness (Breast)

c. Persistent sore throat, lump/ ulcer in mouth, hoarse voice, voice change, tooth ache, nasal blockage, bleeding from the nose (Head and Neck)
d. Abnormal vaginal bleeding (Post coital bleeding, intermenstrual bleeding, post-menopausal bleeding), vaginal discharge (Cervical)
e. Other (Specify?)

[Date of noticing first bodily change]

2. When did you **first** notice the bodily change mentioned above?
   Prompts: Use 'calendar' and best estimate a plausible range to the nearest week)

3. When you first noticed these things, did you think it might be serious?
   a. Yes
      i. Can you tell me why you thought it was serious?
   b. No

[Date of recognizing seriousness/need to visit healthcare provider]

4. When did you **first** think it might be serious?
   Prompts: Use 'calendar' and best estimate a plausible range to the nearest week)

[Duration computation: Pre-Contemplative Stage = Question 4 - Question 2]

5. Did you do any of the following when you first noticed that the bodily change was serious? (*Multiple selections allowed*)
   a. Speak to a friend/family member, If yes, why? In what way did you think they could have helped?
   b. Speak to a community health worker? If yes, why? In what way did you think they could have helped?
   c. Speak to a Chemist/Pharmacist? If yes, why? In what way did you think they could have helped?
   d. Did you consider a traditional healer or attend a traditional healing centre? If yes, why? In what way did you think they could have helped?
   e. How about a religious leader or faith healer? If yes, why? In what way did you think they could have helped?
   f. Did you discuss it on social media or consult the internet? If yes, why? In what way did you think it could have helped?

   For each response, try to find out when in the patient's journey they connected with this person and which was the most important.

[Date of first presentation to a formal healthcare professional]

6. When did you first see a formal healthcare professional following the bodily change? (use 'calendar' and best estimate a plausible range to the nearest week)

[Duration computation: Contemplative Stage = Question 6- Question 4]

7. Who was the formal healthcare professional that you saw?
    a. Doctor
    b. Clinician
    c. Nurse
    d. Other healthcare worker
8. What was the name of the health facility? [Pre-populate list of health facilities in Nairobi]

9. Why did you choose this facility?
   Prompts: Please probe convenience, cost, proximity, confidence, religious obligations, family considerations, quality, social media, other options

[Duration computation: Stage 1 (first delay) = Question 2 - Question 6]

10. What, if anything, hindered you from seeing the health care provider on time?

Here you should explore the causes of any delay –

Prompts: Was it cost? Influence of people - who? Lack of knowledge? Self-denial? Any other?

11. What may have helped reduce the delay to seek help from a formal healthcare professional?

Stage 2: Clinical evaluation, diagnosis and staging
In this section, we will ask you questions to determine the duration of the delays you encountered and the reason behind these delays from when you first saw a formal healthcare provider (mentioned in previous section) to when you were informed about your diagnosis.

1. Can you tell me what happened at the **first** facility where you presented your symptoms?
   Prompts: (***if not diagnosed at the first hospital of call***):
    a. Did the healthcare provider you saw examine you?
    b. After examination, what did the healthcare provider say?
    c. Were you satisfied with the services at your first visit?
    d. Did the healthcare provider refer you? – If so, where to?

2. Did you visit any other health facility after the one mentioned above?
    a. If yes,
        i. When did you go there? (use 'calendar' and best estimate a plausible range to the nearest week)
3. Explore reasons for delay at each referral stage (e.g., lack of funds; belief system – cultural & religious; fear of the unknown; inaccessible hospital; transport etc.)

Repeat question (2 and 3) above for each referral or healthcare provider the patient first visited until they received treatment.

4. From the visits you mentioned, when was a biopsy/tissue sample <u>first</u> taken? (use 'calendar' and best estimate a plausible range to the nearest week)

5. Can you tell me more about when the biopsy or tissue sample?
    a. Was cost/money an issue?

[Date of histological confirmation/given information about diagnosis]

6. When was the information about the histological diagnosis given to you by your doctor? (use 'calendar' and best estimate a plausible range to the nearest week)

[Duration computation: Stage 2 (second delay)] = Question 6 (section 1) – Question 6 (section 2)]

7. What, if any, do you think are the reasons that caused the delay in you receiving information about your diagnosis?
   Here you should explore the causes of any delay –
   Prompts: e.g., personal delays in diagnostic test [funds], clinical delay [bad laboratory], booking/logistics delay, attitude of involving health workers etc.)

8. What may have helped to reduce this delay?

9. After coming in contact with a formal health facility, did you seek healing elsewhere?
   Prompt: Traditional healer, faith healer, faith leader, revival center or healing home

Stage 3: Access to treatment
In this section, we will ask you questions to determine the duration of the delays you encountered and the reason behind these delays from when you were informed about your diagnosis (mentioned above) to when you received treatment.

1. Have you been informed about your treatment?
    a. Yes, continue to next question
    b. No, end interview

2. What was the first treatment you received?
    a. Chemotherapy
    b. Radiotherapy
    c. Surgery
    d. Any other?

[Date of receiving first line treatment]

3. When did you have your first treatment (if not yet started), when is it scheduled? (use 'calendar' and best estimate a plausible range to the nearest week)

[Duration computation: Stage 3 (third delay) = Question 6 (section 1) – Question 3 (section 3)]

4. What, if any, do you think are the reasons that caused the delay in you starting your treatment?
   Here you should explore the causes of any delay –
   Prompts: e.g., lack of funds; belief system – cultural & religious; fear of the unknown; inaccessible hospital; transport etc.)

5. What may have helped to reduce this delay?

6. Do you have any other experience on the diagnosis and treatment of this condition that you want to share?

Thank you for participating.

14 Appendix 3: Consent Form (Attached Separately)