

IMPROVING ACCESS TO CANCER TESTING AND TREATMENT IN KENYA

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ABSTRACT

Louise Makau-Barasa: Improving Access to Cancer Testing and Treatment in Kenya
(Under the direction of Antonia Bennett)

As the third-leading cause of mortality in Kenya after infectious and cardiovascular diseases, cancer poses a challenge to the current health infrastructure. An increase in the number of cancer cases in Kenya over the past ten years resulted in the creation of cancer policies and guidelines to guide delivery of cancer testing and treatment services. Access to these services is limited for the majority of cancer patients in Kenya due to a combination of factors.

This study applied a qualitative analysis approach to determine barriers faced by patients seeking access to cancer testing and treatment, as well as providers delivering these services. The 1974 Andersen and Aday Framework for the study of access to medical care services¹ was applied to respond to the research question, analyze findings and recommend actions in the plan for change section.

Research was conducted in three parts: a literature review, a semi-structured key informant survey and a policy analysis. A purposive sampling technique was used recruit study participants. Fourteen people, including clinicians delivering oncology services and cancer patient support and advocacy group leaders, participated in the key informant interviews. Data from the semi-structured interviews was manually analyzed and five key themes were identified for analysis. These includes financing access to cancer testing and treatment, the level of knowledge and information, the population's health-seeking

behaviors, the locations of cancer diagnostic and treatment services, and policy development and implementation. Further analysis was conducted based on these themes and recommendations on a policy implementation plan formulated.

The limited amount of literature on barriers to cancer testing and treatment in Kenya reduced the scope of available literature for review. The concentration of cancer services in Nairobi, the capital of Kenya, resulted in the use of a limited subset of the population to provide opinions to inform recommendations. Future studies can explore barriers by type of cancer or by demographic group.

To Angelina Malinda Makau Velle:

With gratitude for your love, encouragement and support. Your fight with cancer over ten years gave me hope and inspiration to advocate for access to early cancer testing and affordable cancer treatments in our communities.

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LIST OF ABBREVIATIONS

MOH	Ministry of Health
GOK	Government of Kenya
KNH	Kenyatta National Hospital
KNCI	Kenyan National Cancer Institute
KENCO	Kenya Network of Cancer Organizations
AMREF	Africa Medical Research Foundation
ESRC	Ethics and Scientific Review Commission
UNC	University of North Carolina
IRB	Institutional Review Board
CP	Clinical Participant
NCP	Non-Clinical Participant

CHAPTER 1: INTRODUCTION

Cancer is one of the four ¹ non-communicable diseases (NCDs) posing a significant social and economic burden globally, but particularly in Low and Middle Income Countries (LMIC) where access to cancer treatment is limited by social, economic and systemic factors. Scientific evidence supports a strong association between tobacco usage, excessive alcohol consumption, and the consumption of foods with high levels of fat, sugar and salt content – all of which carry a higher cancer risk. Other associated factors include genetic composition, exposure to carcinogens, toxins and toxic substances ² and, in some studies, the use of a combination of certain oral contraceptives ³ have also been attributed to the development of certain cancers in women.

In 2012, the International Agency for Research on Cancer Research (IARC), a World Health Organization (WHO) agency, reported 14.1 million new cancer cases, 8.2 million cancer deaths and 32.6 million people living with cancer (within five years of diagnosis) worldwide. That is projected to reach 26 million by 2030 ⁴. Of these, 8 million (57%) of these new cancer cases, 5.3 million (65%) of the cancer deaths, and 15.6 million (48%) of the five-year prevalent cancer cases occurred in less developed regions ^{4, 2}.

¹WHO lists the four NCDs as cardiovascular diseases, cancer, chronic respiratory diseases and diabetes

²WHO classifies the less developed regions as countries in South-Eastern Asian, Eastern Africa, Central America, Western Africa, Northern Africa, Middle Africa and South-Central Asia.

Africa reported 847,000 new cancer cases (ASR ³ 123.4 per 100,000) and 591,200 cancer deaths (ASR 89.8 per 100,000) in 2012 ⁵. However, these figures could be underestimated due to the lack of appropriate cancer diagnosis services, sub-optimal access to cancer testing and treatment services, and the lack of health systems to report the extent of the cancer burden ⁶.

In East Africa, Kenya has the highest number of reported cancer cases, ranging from 22,000 new cases per year ⁷ to 41,000 new cases per year (ASR 181.8 per 100,000) ⁵, while the cancer mortality rate was reported at 28,000 per year (ASR 135.3) ⁸. The wide range of incidence rates is an indicator of the lack of data resulting from a weak cancer registration system in Kenya, which is not unlike registries in many low and middle income countries ⁹. Table 1 below presents a comparative summary of the global burden of cancer in the world, Africa and Kenya. The aim of this table is to allow readers to understand the significance of this study for Kenya's public health sector. Based on the data source, the new cases shown in the table below represent population weighted average of the area-specific rates applied to the 2012 area population ⁴.

³An age-standardized rate is the rate that a population would have if it had a standard age structure. It is based on the number of new cases or deaths per 100 000 persons per year. Standardization is necessary when comparing several populations that differ with respect to age because age has a powerful influence on the risk of cancer.

Table 1. A Comparative Summary of Cancer Incidences in the World, Africa and Kenya⁵

Geography	Population (thousands)	New Cases (2012)⁵ (thousands)	Age-standardized Incidence Rate	Risk of getting cancer before age 75⁴
World	7,054,446	14,067.9	182	18.5%
Africa	1,072,406	847	123	12.8%
Kenya	42,479	41	181.8	19%

Cancer represents the third-leading cause of mortality in Kenya after infectious and cardiovascular diseases; 60% of cancer patients are younger than 60 ⁷. Whereas 48% of the cancer deaths in LMICs are premature (under the age of 70), only 26% of cancer deaths fall under the same category in high-income countries ¹⁰. Among men, prostate is the most common cancer with a five-year prevalence rate of 21.5% and 6,577 deaths⁵.

Among women, cervical cancer has the highest incidence rates (20.5%), however breast cancer has higher mortality rates with an average five-year prevalence rate of 27 % or 14,070 cases, compared to 23% and 12,338 cases, respectively, for cervical cancer ⁵.

1.1 Significance of the Issue

HIV/AIDS and perinatal conditions remain the leading causes of death in Kenya and the emergence of non-communicable diseases are causing a significant strain on Kenya's health system ¹¹. As the third-leading cause of mortality in Kenya, cancer is posing unique challenges to the current health infrastructure, while also affecting a much younger population when compared to populations in other countries. In Kenya, the risk of dying of

⁴Risk of getting or dying from the disease before age 75 (%): The probability or risk of individuals getting/dying from cancer. It is expressed as the number of new born children (out of 100) who would be expected to develop/die from cancer before the age of 75 if they had cancer rates (in the absence of other causes of death).

cancer before the age of 75 is high (14.5%), as compared to 10.5% globally and 9.4% in Africa ⁴. Currently, access to cancer testing and treatment in Kenya is provided by 12 health facilities, the majority of which are located in urban areas. Most of these services are available in Nairobi, the capital of Kenya.

This study is relevant to ongoing stakeholder discussions to strengthen Kenya's cancer prevention and control efforts by focusing on four main components:

1. cancer research
2. pathology and cancer registries
3. cancer awareness and education
4. national healthcare systems and infrastructure

In addition to these initiatives, the 2015 amendments to the current Cancer Act ¹² are indicative of the need to continue revising the current legal framework that governs the provision of cancer services in Kenya, and as further explained by this study's findings and recommendations in the plan for change section.

This research will identify barriers faced by patients seeking access to cancer testing and treatment services in Kenya, in order to address the overarching question: *How can access to cancer diagnosis and treatment be improved in Kenya?* In this study, testing was defined as both screening and diagnostic testing.

1.2 Study Purpose

The purpose of this study is to generate knowledge and inform policy in order to improve the timely access to cancer testing and treatment services in Kenya. Three research questions will be addressed with the following specific aims:

Research question 1: What are the patient characteristics, including level of cancer awareness, among people seeking access to cancer testing and treatment services and which of these are modifiable through policy or other actions?

Aim 1: To identify and seek to understand barriers faced by patients seeking access to cancer testing and treatment services in Kenya by conducting semi-structured interviews with cancer advocacy group leaders.

Research question 2: How does the organization of health services and the health infrastructure affect access for patients?

Aim 2: To identify and seek to understand barriers faced by patient providers who are delivering cancer testing and treatment services in Kenya by conducting semi-structured interviews with clinicians.

Research question 3: What policy actions can improve access to timely cancer testing and treatment in Kenya?

Aim 3: To identify potential policy level actions that could be recommended to the legislature in order to improve access and delivery of cancer testing and treatment services in Kenya by integrating results of the qualitative interviews with a policy review.

1.3 Background on Health Service Delivery in Kenya

In 2010, Kenya's constitution changed the governance of Kenya's health sector, beginning with the merging of the former Ministry of Public Health and Sanitation (MOPHS) and the Ministry of Medical Services (MOMS) (2008 - 2012) into one body: the Ministry of Health. This merger called for the devolution of health services to the county level ¹³. These changes led to the reallocation of budgets and functions between the national and county levels, with the former retaining national policy creation and the latter implementation. Under this new arrangement, the government prioritized preventive primary care, health

workforce development, infectious disease control, policy development, health quality assurance and standards ¹⁴. However, the management and control of NCDs – including cancer – remained a function of the primary under primary healthcare.

In 2016, Kenya reported a total of 10,795 health facilities, including dispensaries (clinics) and health centers, which reflected a 25% increase over the 8,496 health facilities recorded in 2012 by the Ministry of Health ¹⁵. In 2012, 49% of the health facilities were public, 33% were private and for-profit, and 16% were private and not-for-profit. During the same period, the doctor to population ratio was <1:10,000; nurse to population ratio 3:10,000 and the registered clinical officer to population ratio 1:10,000 ¹¹. Kenya also has a total of 11 radiation oncologists ¹⁶ and about 10 medical oncologists ¹⁷.

Based on the organization of health services in Kenya, national level actions include ¹⁸:

1. Setting national policies and legislation that established standards, national reporting, sector coordination, and resource mobilization
2. Offering technical support, with emphasis on planning, development, and monitoring of health service delivery quality and standards throughout the country
3. Providing guidelines on tariffs chargeable for the provisions of health services
4. Promoting mechanisms for improving administrative and management systems, including conducting appropriate studies
5. Capacity building of county governments to effectively deliver high-quality and responsive health services

The county government departments and entities responsible for health have the duty of establishing structures, departments and entities to coordinate and manage delivery of the constitutionally defined health mandates and services at the county level ¹⁹. These include:

1. County health facilities and pharmacies
2. Ambulance services
3. Promotion of primary healthcare
4. Licensing and control of undertakings that sell food to the public
5. Veterinary services (excluding regulation of the profession)
6. Cemeteries, funeral parlors, and crematoria
7. Refuse removal, refuse dumps, and solid waste disposal

In addition to the above functions, county governments may be assigned other functions that were agreed to during the intergovernmental consultative forums. The county is also tasked with taking a lead role in advising, mobilizing, and collaborating with other government ministries, departments, and agencies ¹⁹.

1.3.1 Cancer Treatment Facilities

Kenya has a total of 12 cancer treatment hospitals: seven private, two mission and three public. It also has four radiotherapy centers ¹⁵. Of the public ones, only Kenyatta National Hospital (KNH) in Nairobi is equipped to provide the three major cancer treatment modalities: surgery, radiotherapy and systemic (chemotherapy). Moi Teaching and Referral Hospital (MTRH) in Eldoret and Coast General Hospital can provide surgery and systemic therapy, but plans are underway to equip them with radiation units. Three of the private hospitals – MP Shah, Aga Khan and Nairobi Hospital – are equipped to provide the full treatment modalities with the rest, mission hospitals included, only able to undertake surgery and systemic therapy. See Appendix 1: List of Cancer Testing and Treatment Facilities in Kenya” for the full list of cancer service providers in Kenya.

1.3.2 Financing Health Services in Kenya

A breakdown of Kenya's health expenditures in 2012-2013 indicated a larger allocation of the health spending to infectious diseases – HIV/ AIDS (20%) and malaria (9.8%) – and reproductive health (12.9%). Respiratory infections, vaccine-preventable diseases, and non-communicable diseases each accounted for roughly 6% of the total health budget or 0.4% of the GDP¹¹. Specifically, the non-communicable diseases budget amounted to KSh 14.6 billion (USD \$170 million) in 2012-2013, with 90% being spent on current health expenditures and the remaining 10 percent on capital formations¹¹.

The above figures reflect a slight increase in the total health budget from KSh 163 billion (USD \$2.155 million) in 2009-2010 to KSh 234 billion (USD \$2.743 million) in 2012-2013, partly due to a reduction in donor funding for Kenya's health sector. Overall, Kenya's total health expenditure, as part of total government expenditures, fluctuated from 8% (2001-2002), 5.2% (2005-2006), 4.6% (2009-2010) to 6.1% (2012-2013) ¹¹.

During the same period (2012-2013), revenues to finance healthcare in Kenya came from three major sources: the government (31%), households (32%), and donors (26%). The remainder came from corporations (10%) and other sources (1%) ¹¹. From these sources, the private sector was the major financier, contributing 40% of total health expenditures. This reflected an increase of 37% in 2009-2010. Comparatively, during the same period the public contributed 34%, an increase of 17 percent over the 2009-2010 estimates¹¹.

1.3.3 Kenya's Health Policies

In 2011, the National Cancer Control Strategy (2011-2016) was produced by the Ministry of Public Health and Sanitation and the Ministry of Medical Services in response to the need to prioritize cancer prevention and control in Kenya ²⁰. This was followed by the creation of Kenya's Cancer Prevention and Control Act in 2012 (Amended in 2015) ²¹ as a regulatory and national framework to address cancer as one of the emerging non-communicable diseases in the country. In 2013, the National Guidelines for Cancer Management were published by the government to provide guidance to clinical providers tasked with screening, diagnosing and treating cancer ²². In 2015, Kenya's National Cancer Institute Board was elected to oversee the implementation of the cancer bill and coordinate national activities and cancer services providers, mostly targeting awareness and treatment ²³. These policy documents and actions have laid the framework for addressing the existing cancer burden.

These recent legislative developments surrounding the provision of medical services to diagnose and treat cancer are an indicator of the momentum to respond to the increasing cancer burden in Kenya.

As such, this study will seek to further identify and communicate barriers faced by patients seeking access to diagnostic and treatment services for cancer in the country, and barriers faced by practitioners delivering cancer diagnostic and treatment services and ways they can be addressed.

The study is conducted in three parts and the results of each will inform the overarching research question: "How can access to Cancer Testing and Treatment Be Improved in Kenya?"

Part 1: A literature review on cancer incidence, prevalence and mortality rates, as well as the barriers to cancer testing and treatment in Kenya was conducted and results are presented in Chapter 2.

Part 2: Semi-structured key informant interviews were conducted to further identify and understand barriers faced by people seeking cancer testing and treatment in Kenya, from the perspective of patient support and advocacy groups (Aim 1), and clinical cancer services providers (Aim 2). The qualitative methods are described in Chapter 3 and the results of the interviews are presented in Chapter 4.

Part 3: An analysis of Kenya's current cancer policies was conducted. This analysis was informed by a review of policy literature (Aim 3). Policy-focused literature sources included government policy documents and guidelines identified through the Ministry of Health and informal conversations with policy makers and research articles identified through PubMed. Further, a section of the semi-structured key informant interviews sought the opinions of the participants on the current cancer act and its effect on patients and providers in the cancer sector. These findings are brought to bear on the policy analysis. The policy literature review is presented in the policy implementation recommendations in Chapter 7 and the plan for change in Chapter 8.

CHAPTER 2: LITERATURE REVIEW

A literature review was first conducted from September 2014 to March 2015. In this first phase, an extensive review of published peer reviewed literature and newspaper articles from Kenya's leading newspapers highlighting cancer access and policy articles was conducted. A revision was conducted in January 2016 to capture articles that had been published after March 2015. The results of both exercises indicated barriers faced by patients seeking access to cancer testing and treatment, and barriers faced by clinicians delivering the services. The following strategy was applied and the results used to inform recommendations in the plan for change.

2.1 Search Strategy

An online search for peer reviewed and indexed articles was conducted through PubMed. PubMed was selected due to its access to a wide range of indexed medical journals, including context relevant ones, such as the East African Medical Journal where most full manuscripts on cancer and Kenya were located. The search terms included "Neoplasms"[Mesh] AND ("Kenya"[Mesh]) and (test OR testing OR treatment OR screening OR access)" to identify articles reporting barriers to cancer testing and treatment in Kenya. The terms "Cancer Policy in Kenya OR Africa" was applied in search of policy literature to complement existing government literature produced by the Kenya government and other stakeholders. Variations of these terms yielded a varying amount of articles with most of the relevant ones included in the PubMed results. Search results were first saved

online in an NCBI⁵ folder then exported to Refworks – an online data management software where the articles were filtered using titular relevance and then analyzed.

2.2 Inclusion, Exclusion Criteria

To be classified as relevant, articles were required to have one or all of the search terms and have been published between January 2000 and January 2016. Articles published before the year 2000 were excluded due to changes in Kenya's cancer sector over the past 15 years. Language was limited to English. Also excluded were articles whose titles included terms such as "Low and Middle Income Countries (LMIC)," "Africa," or named a different country other than Kenya. These were deemed too general and not applicable to the country-specific information relevant to this study.

2.3 Literature Review Process

The search yielded 360 articles through PubMed, out of which 204 were preselected based on titular relevance and 38 qualified for a systematic review. Of these articles, 34 identified barriers to treatment and suggested interventions to improve screening, diagnosis and treatment. Four articles focused on policies and policy level actions that could address existing patients and provider barriers to screening, testing and treatment in Kenya. A systematic review of the full articles was conducted in the following manner:

Step 1: The titles of all the search results (n=360) were checked for titular relevance based on the search terms and 204 articles were preselected, based on a match to most of the search terms.

⁵The National Center for Biotechnology Information advances science and health by providing access to biomedical and genomic information

Step 2: Abstracts were screened and about 60 abstracts were selected based on their potential to respond further to the research questions. Some 22 abstracts were further excluded for lack of the full article. After further analysis of the full manuscripts, 38 articles were retained based on the search criteria and relevance to the study. The literature identification and selection process is presented below (Figure 1).

Step 3: Each study's profile: publication date, type, authors, type of cancer studied, and the results were tracked in an Excel table that was later used to document and reference the studies' findings (Appendix 2: Literature Review Results Tracking Table).

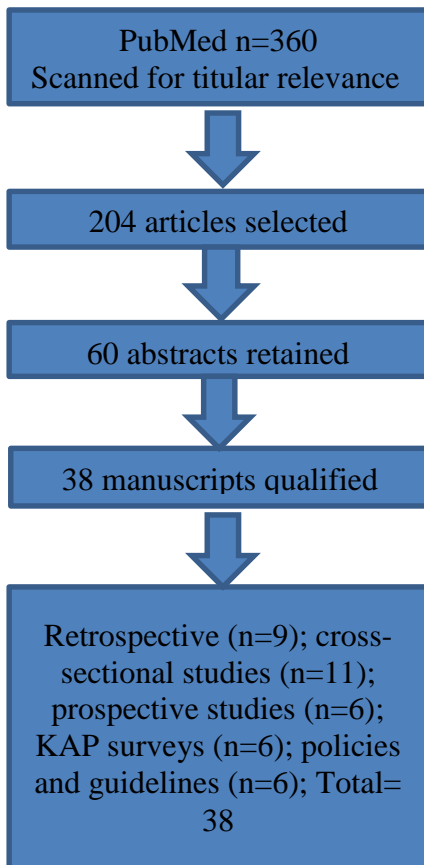


Figure 1. A Schema of the Literature Identification and Qualification Process

2.4 Literature Review Search Results

The literature review results were organized into two sections: 1) Barriers to screening, testing and treatment – mainly reported by patients and, in a few cases, by clinical providers. These were first sorted out by type of cancer followed by themes identified from the literature; and 2) policies and interventions that could improve access and uptake of the aforementioned services.

2.4.1 By Type of Cancer

Studies were sorted out by type of cancer for comparative purposes. Cervical (n=16), Breast (n=7), Childhood Cancers (n=6), Esophageal (n=1), Gastric (n=1), Head and Neck (n=1) and Prostate Cancer (n=1); various cancers (n=1). For each of the studies on specific cancers, data was collected from patients, relatives and in some of the healthcare providers in health facilities providing cancer testing or treatment (Figure 2).

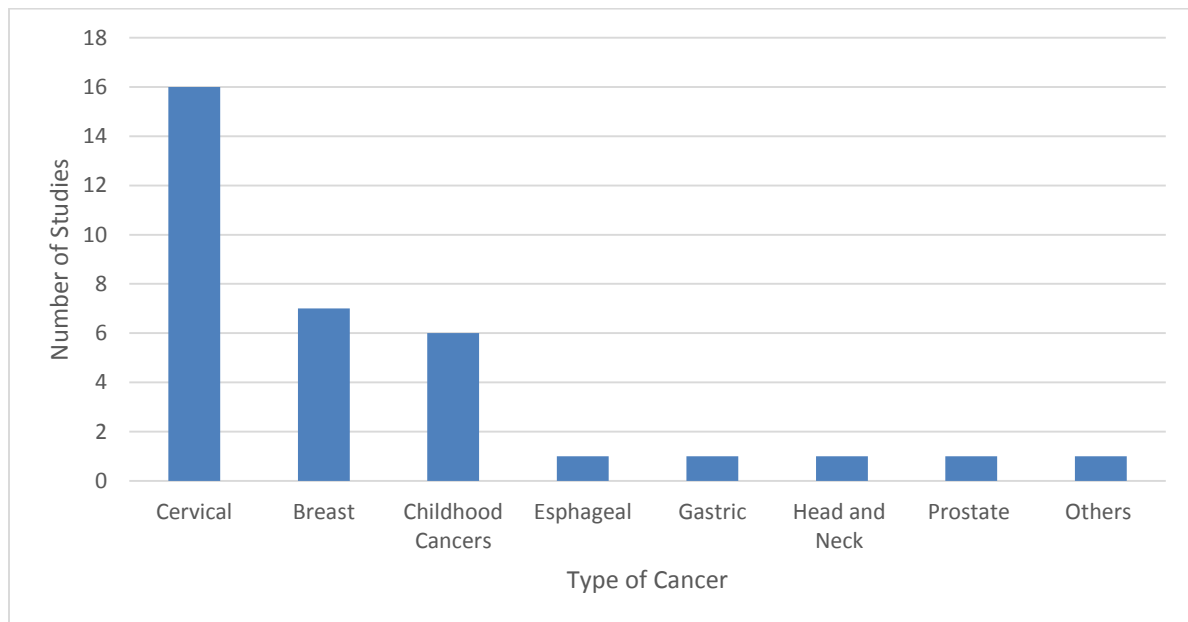


Figure 2. Presentation of Literature Review Results by Types of Cancer

2.4.2 By Types of Barriers

A lack of knowledge and information about their specific cancer was the challenge most often cited by patients, and a reason for late presentation when the cancers were advanced (n=11). Transportation costs and health provider service fees – consultation charges, testing, diagnosis and treatment costs – were the second-most common barrier cited (n=10). Fear of cancer due to stigma and its association with death was cited as the third leading reason (n=9) for not seeking immediate treatment, and or seeking alternative justifications for their symptoms. Difficulty accessing health providers due to distances and or long wait times was reported in four of the studies, while poor health provider attitudes – especially for cervical cancer due to its association with HIV/AIDS – was reported as a deterrent by patients seeking cervical cancer screening (n=4). Inadequacy of health providers to accurately screen and or diagnose cancer was reported in at least four articles (n=4), leading to misdiagnosis or sub-optimal treatment of patients (Figure 3).

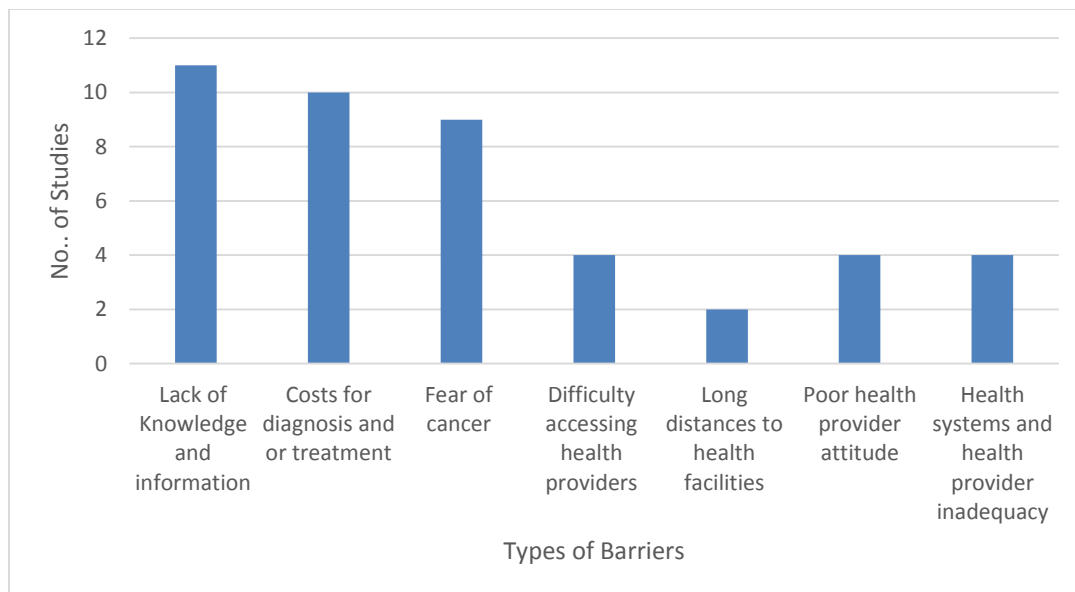


Figure 3. A Summary of Barriers Faced by Patients Seeking Cancer Testing and Treatment in Kenya

2.5 Findings

Overall, medical costs pose a significant barrier to accessing cancer services. Patients with public insurance known as the National Health Insurance Fund (NHIF) were more likely to complete treatment as compared to those without any insurance ^{24, 25, 26}. Hospital policies on detaining patients in hospital for unpaid bills were noted as a significant barrier to accessing treatment ^{24, 25}.

Studies on cervical cancer in Kenya indicated that patient barriers included fear of the disease ^{27, 28, 29, 30, 31, 32, 33, 34} and financial difficulties to access treatment due to the location of the health services ^{33, 35}. Lack of support to access screening services, which were in some cases located far from their homes, was reported by women ³³.

Poor provider attitudes and stigma for patients seeking cervical cancer screening was commonly cited as a deterrent to screening and treatment by women ^{36, 33}. However, men's attitudes leaned toward supporting timely screening of their partners despite only half of those interviewed perceived their partners to be at risk ³⁶.

A lack of provider skills, and in most cases, the medical equipment to accurately screen, diagnose and treat cancer is a significant barrier to effective identification and treatment of cancers ^{30, 35}. Kenyatta National Hospital (KNH) in Nairobi and the Moi Teaching and Referral Hospital (MTRH) in Eldoret received 70% of cervical cancer cases in the country ²⁹. This means patients from all over the country are more likely to travel to these two hospitals for treatment, which contributes to the long wait times that sometimes average three to four months, based on patient reports ^{28, 30, 34}. Women over 30 years old were more likely to have been screened than younger ones ^{34, 37}. Training primary care clinical staff to test for cervical cancer using visual inspection with ascetic acid (VIA) or Lugol's Iodine ^{27, 30}

could reduce the amount of time lost by patients through the referral system and bring services closer to the most affected areas and susceptible groups.

Patients with late presentation for breast cancer were classified as those whose cancer had progressed to stage IIB, III or IV ^{38,39}. Testing was conducted at health facilities using physically palpable nodules, tissue biopsies, ultrasounds and CT scans ³⁷. MRI was not widely available in the hospitals, requiring patients to travel long distances mostly to the national hospital (KNH) for MRI and additional testing. Tissue biopsy analysis was also not available in most of the studied county level hospitals ⁴⁰. The lack of these services resulted in treatment delays for patients and further contributed to poor outcomes for cancer patients ³⁹. Results also indicated an early onset of breast cancer among Kenyan women, 35 to 45 years of age, which is 10 years earlier than onset in Caucasian women. A more aggressive and estrogen negative cancer was reported among the majority of patients ⁴¹. Women with a family history of breast cancer had an 18.8% risk of developing cancer, had higher rates of metastases at 88% by the time of presentation, and could benefit from targeted genetic testing to improve their outcomes. Awareness of familial cancer risk is important for targeted screening and testing ³⁹.

Only one facility in the country is equipped to carry out advanced testing that could result in targeted therapy using well-known drugs that have better patient outcomes ³⁵. Inadequately trained staff are unable to identify patients at risk of cancer and perform screening tests that could lead to timely diagnosis and treatment, resulting in a reduction in cancer-related morbidity. One of them demonstrated that nurse training at one of the teaching hospitals (Aga Khan University Hospital) had positive outcomes in initiating patient testing and raising awareness about cancer among patients ⁴¹.

Childhood cancer studies reported low survival rates and a significant amount of late presentation of cases in at least 85% of the cases^{28, 24, 33}. High transport costs to the medical facility, lack of parental awareness about the disease, poor communication by the providers and a scarcity of pediatric oncological services were reported as major barriers faced by parents of children diagnosed with a pediatric neoplasm^{28, 24, 33, 26}. Insured patients had higher treatment completion rates and a higher chance of an event-free survival two years after treatment as compared to uninsured patients^{24, 33, 37}.

Kenyan hospital policies of detaining patients due to lack of payment was a significant barrier to treatment compliance and completion. Such policies need to be abolished and instead supportive mechanisms put in place through the NHIF to ensure that patients are protected from hospital policies that are detrimental to their health^{30, 24, 37, 42}. Data on the extent of childhood cancers in Kenya is scant and could be an indicator of a lack of reporting or misdiagnosis at the provider level.

Patients faced with other cancers Esophageal (n=1), head and neck (n=1), gastric (n=1) and prostate (n=1) presented late in over 50% of the cases, largely due to lack of information about their diseases^{43, 44, 45}

Provider-side barriers included lack of competence by staff who were unable to diagnose potential malignancies and refer patients to specialists^{27, 33, 37, 41}. In-service nurse training was reported to be an effective approach to increasing provider-initiated screening, as well as upskilling nurses' ability to detect cancers, such as cervical and breast, especially in low-resource settings within the country⁴¹. Negative provider attitudes toward cancer patients, cultural beliefs, taboos and personal discomfort in physically examining older clients or clients of the opposite sex contributed to difficulties faced by service providers⁴⁶.

However, targeted screening and early diagnosis was reported to increase the likelihood of effective treatment ^{38, 35}.

2.6 Limitations

The literature search focused on peer-reviewed articles found mainly through PubMed. Every effort was made to retrieve the full manuscripts of journals indexed at PubMed, however, manuscripts were occasionally unavailable for further review, thus potentially leaving out relevant articles. By limiting the search period from 2000 to 2015, other relevant articles could have been excluded. However, delimiting the time period yielded a limited number (<10) relevant articles with more than five of the full manuscripts unavailable for further analysis.

A comparative analysis of barriers to cancer care by cancer type was not possible due to the wide variety of cancers in the small number of articles. Instead, results were grouped across cancer types by theme. In the current review, the population characteristics are not taken into account since the primary focus is on the type and impact of barriers on the patients' health outcomes.

Existing literature points out gaps that can be addressed to improve the timely access to cancer testing and treatment services in Kenya. Focusing on the top three adult cancers and the group of pediatric cancers can serve as a starting point towards improving the diagnosis and treatment services in the country.

CHAPTER 3: QUALITATIVE INTERVIEW METHODOLOGY

Qualitative research dates back to the late 19th century post positivism era with the application of phenomenology by the German philosopher Edmund Husserl (1859-1938) and the development of anthropology by Franz Boas (1858- 1942). Most recently, qualitative research gained in importance “... after 1970 with the emergence of postmodernity, signaling a new dynamic, multi-perspectival, and emergent social complexity that cannot easily be captured with the use of quantitative methods...”⁴⁷. Qualitative research allows the researcher to obtain the opinions and perceptions of key informants. It attempts to explore the relative nature of knowledge, which is subjective, unique and contextual⁴⁸. It also allows the researcher to understand a particular situation or event⁴⁹. As an investigative process, it allows for a deeper understanding of specific events, in this case a health phenomenon. Focusing on the participants’ perceptions and experiences, it attempts to understand multiple realities⁴⁹ faced by participants in relation to the study topic. It acknowledges the changing nature of people and phenomena that make it inappropriate to generalize results to the wider population or phenomena being studied, unless the readers resonate with the findings of the study and choose to transfer them to comparable contexts. Qualitative research also allows the researcher to connect the ideas and patterns observed through interviews and data analysis, in a congruent manner, to the research objective and the resulting implications of the study⁴⁸.

As such, this study applies a qualitative approach to understand barriers, perceived or real, that hinder the delivery of and access to cancer testing and treatment services in Kenya.

Additionally, a conceptual framework was applied to the study design and interpretation of findings, and their use to respond to the study's research questions and aims as shown in the following section.

3.1 Conceptual Framework

The 1974 Andersen and Aday Framework¹ integrates definitions and concepts of access to medical care services into a framework "...that views health policy as designed to affect characteristics of the health care delivery system and of the population at risk in order to bring about changes in the utilization of health care services and in the satisfaction of consumers with those services.¹" In this study, this framework was applied to demonstrate barriers faced by patients seeking cancer testing and treatment services and providers delivering these services in Kenya. Revised versions of this framework have been published by the authors, however, the 1974 version was selected for this study due to its ability to demonstrate how access to cancer care in Kenya can be improved through policy actions.

This framework postulates that three variables need to be considered in policy oriented studies: (1) the outcomes of the utilization of the health services; (2) the changeable factors (mutable variables) amenable to policy actions; and (3) the factors that affect health outcomes, but cannot be changed by policy actions. Figure 4 (below) is a schematic presentation of this framework and the juxtaposition of the above three variables and their influence over access to health services, such as cancer care.

Barriers to Cancer Testing & Treatment Presented Using the Andersen & Aday Health Access Framework

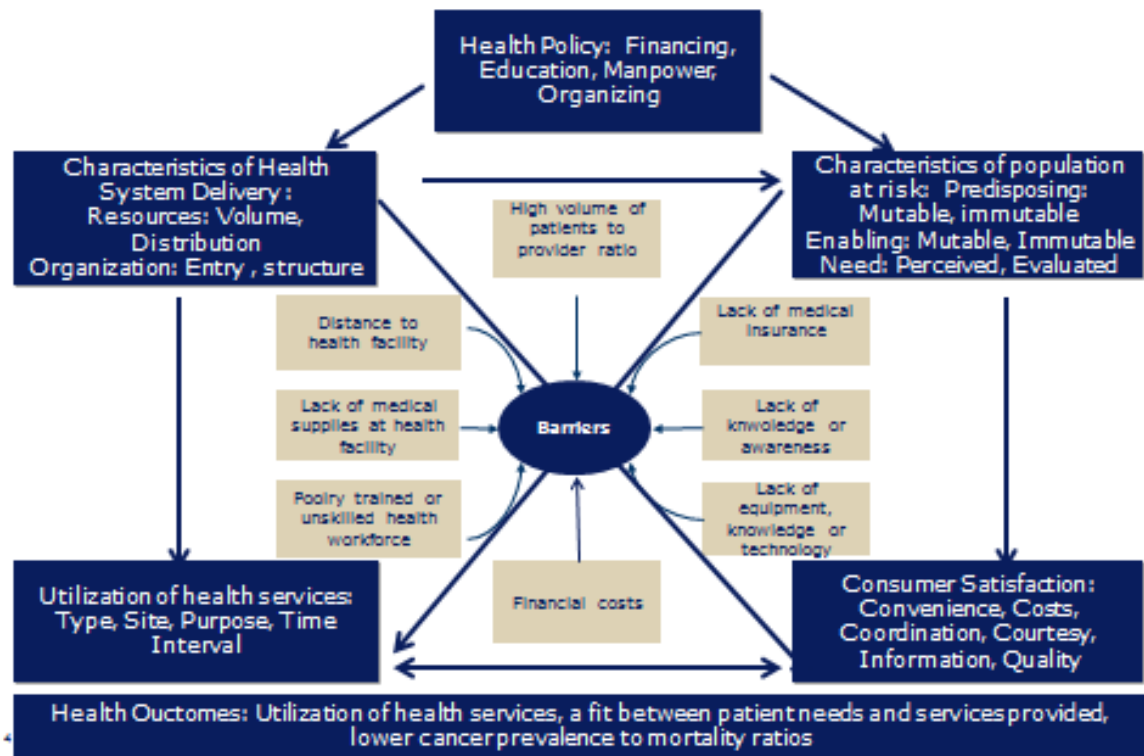


Figure 4. Conceptual Framework for Studying the Barriers to Accessing Cancer Testing and Treatment Service in Kenya

3.2 Application of the Framework

This framework was used to assess current practices to cancer testing and treatment in Kenya and informed the analysis of the key informant interviews. The roles of each of the key players in the health sector were examined using the framework.

- 1. Patients:** This study examines the role of patients in overcoming barriers using the factors identified in the framework under “characteristics of the population at risk,” with a focus on identifying mutable factors that can be affected by policy actions, such as access to the national and private health insurance schemes. Immutable factors are those

that are non-responsive to policy changes, such as patient demographics (age, income and education levels) and their influence on the population's health-seeking behaviors.

- 2. Clinical Providers:** This study examines the role of doctors and the barriers they face in the delivery of cancer testing and treatment services using variables identified under the “characteristics of the health system delivery” by Aday and Anderson¹. Some of the examined characteristics include the availability of oncologists to the population, patient wait times, the delivery and organization of cancer testing, and treatment services, including patient follow-up.
- 3. Health Infrastructure:** This study examines the characteristics and availability of cancer testing and treatment services in the country. This includes identifying the types and locations of cancer diagnostic and treatment services available in the country, and their capacity to respond to current patient demand.
- 4. Patient Support and Advocacy Groups:** This study examines levels of patient satisfaction, as reported by the leaders of cancer patients and survivors support and advocacy groups, with the current cancer testing and treatment services. This aspect includes the ease of access, related access costs, the coordination of cancer care within and outside the delivery setting, availability of information and provider-to-patient communication.
- 5. Government:** This study examines the role of Kenya's current cancer policies as stipulated by Kenya's government through the Ministry of Health's “National Cancer Control Strategy” and Kenya's Cancer Prevention and Control Act, 2012 (amended 2015) and other policy literature. This includes a review of the organization of care from the point of entry through treatment and follow-up.

3.3 Study Design

A series of key informant interviews targeting cancer clinical providers (clinicians) and leaders of cancer patient support and advocacy groups (non-clinical) were conducted in January 2016. The objective of these interviews was to supplement information obtained from the literature review and to gain a better understanding of barriers faced by patient's seeking access to cancer testing and treatment through discussions with leaders of cancer patients and survivor group representatives and clinical providers. The second objective was to collect the opinions of these two stakeholder groups on how Kenya's current cancer policy can be improved.

3.4 Study Setting

The study was conducted via phone (n=3) and face-to-face (n=11) interviews in Nairobi. Apart from interviews conducted over the telephone, clinical providers (n=6) were interviewed in one public hospital, two private and one mission hospital. Non-clinical providers (n=5) were interviewed at meeting locations in Nairobi.

3.5 Sample Criteria and Selection

Study participants were selected for one of two main categories: 1) serve as medical practitioner, doctor or clinician delivering cancer testing and treatment services in Kenya (clinicians); or 2) serve as a cancer patient support and advocacy group leader (non-clinician). People who met this criterion were invited to participate in the key informant interview.

Additional information and the objective of this study was provided via email to the potential interviewees using the study information and participant consent form. A follow-up phone call to each respondent was used to further explain the study objectives, respond to questions and schedule the interview.

The initial goal was to interview up to 20 key informants. However, once saturation was obtained by the tenth interview, an additional four participants whose interviews had been scheduled were interviewed to ascertain that saturation had been attained. In this study, saturation was defined as having been reached when no new themes emerge from the participants in response to the interview questions, as described in “Applied Thematic Analysis”.⁵⁰

3.6 Sampling Technique

The concentration of cancer services within Nairobi results in the concentration of clinicians within the four health facilities (in Nairobi) with comprehensive cancer services. These concentrations influenced the purposive sampling technique applied to identify potential study participants who were recruited in two phases: 1) through personal contact and introductions to key cancer sector experts and policy makers Kenya; and 2) using direct emails to organizations listed in the Kenya Cancer Network Organization (KENCO) website and published articles. In both cases, information about the study was shared through email and using a standard study information document approved by the ESRC and UNC’s IRB board. Names and the contact information of additional participants were shared by some of the participants during the interviews. This personal approach was most suitable to further explain the study’s objectives and secure participation in the study. It was also observed to increase the response rate when compared to the initial emails sent to contacts identified through the KENCO website.

Altogether, a total of potential 45 participants, 24 clinicians, 17 cancer support group leaders and four policy makers were identified and contacted through email. An invitation to participate in the study was extended to the 45 identified potential participants between November 2015 and January 2016. More than half (n=25) of those contacted responded

between December 2015 and January 2016. Initial conversations with each of the respondents were used to further explain the study and determine whether the respondent met the participant criteria (clinician or leader of a cancer patients and survivors support and advocacy groups).

A total of 25 people who responded and met the criteria were contacted and a tentative interview time was set up. Although the study's target was 20 key informants, this higher number was taken to accommodate the likelihood of some of the respondents not being available at the time of the interview. Non-respondents were excluded from the study after three contact attempts with no response. Five respondents who confirmed in the affirmative after January 24 were excluded due to time constraints, feasibility and study saturation.

3.7 Data Collection

A review of the study procedures, including the estimated duration of the interviews, was described again in detail to the participants before the beginning of each interview to enable participants to be fully informed of their time requirements and to freely consent or decline to participate in the study. Prior to each interview, signed consent was obtained by email for the three telephone participants and in person for in-person interview participants (Appendix 3- Study Information and Consent Form). All interviews were conducted in English. Telephone interviews were held during the evening hours for the participants. This was done to accommodate the participants' schedule and due to the eight-hour time difference between the participants in Nairobi and the investigator's location in Malvern, Pennsylvania. The in-person interviews were conducted from Jan. 18 to 24, 2016, and as scheduled by the participants and investigator. The earliest interview was conducted at 9 am and the latest at 6.30 pm. Interviews lasted between 14 minutes and 45 minutes, averaging 30

minutes per participant. Verbal consent was obtained from the participants at the beginning of each interview. A thank-you note was sent via email to each participant three weeks after the interviews.

Overall, a total of fourteen (n=14) key informants participated in the study. Eleven of the 14 participants were interviewed in person at the study site in Nairobi, and three participants were interviewed by telephone. Five participants were unavailable at the scheduled times of their interviews. One confirmed participant backed out of the study, citing a fear of meeting strangers. The participant interview guide (Appendix 4: Key Informant Interview Guide) was used to collect information from the participants. This interview guide has two separate sets of questions for the two types of key informants – one for clinical personnel and second for non-clinical personnel. Further probing was done when the participants seemed to have more to say in response to a question. This was done to ensure that additional and potentially relevant information was captured. Questions designed for clinicians were varied for the pathologists (n=2) to accommodate their role and not directly dealing with patients in the same manner as the other clinicians (oncologists and surgeon). Where a question was not applicable, it was skipped or marked as not applicable (N/A) (Appendix 5: Example of Transcribed Responses)

The interviews were recorded using the voice memo application on the iPhone5. These voice memos were transcribed into text using Microsoft Word. Notes were also taken during the interview to note interesting quotes and points where further inquiry would be required. Each participant was assigned a unique identification code to protect their identity and reduce the risk of linking responses to individuals and their institutions. Additional steps to safeguard the identity of the respondents included:

1. The secure storage of all written and audio transcripts in a locked cabinet in the principal investigator's office.
2. Password protection of the collected data on a computer at the principal investigator's office.

3.8 Data Analysis and Interpretation of Interviews

Following the interviews, and using Creswell's systematic approach to data analysis (Figure 5), data was transferred from the voice memos to a password protected computer file in the principal investigator's home office. The files were organized and listened to for clarity before being sent electronically to two individual transcribers located in the study setting (Nairobi). This approach was necessary to accommodate language nuances and translate any Kiswahili (Kenya national language) terminology used by respondents. The written transcripts were verified against the audio recordings to ensure that critical information had been captured.

All data was reported in aggregate terms to protect the identity of participants and their organizations. The data was stored in compliance with the UNC IRB and the AMREF ESRC requirements.

Upon completion of this step, the transcripts were read to get a general idea of the information received. These were then organized in the two participant categories—clinicians (medical personnel) and non-clinical personnel (cancer patient support and advocacy group leaders). This was done to enable the identification of themes per respondent group.

One of the clinician's responses were inaudible and could not be effectively transcribed. As a result, only 13 participants' responses were analyzed and presented in the following sections.

3.9 Ethics Statement

This study was approved by the ethical review board at the University of North Carolina, North Carolina, in May 2015 (IRB number 13-4105) and the Africa Medical Research Ethics and Scientific Review Committee (AMREF- ESRC) under study number P199/2015 in November 2016. An amendment to accept electronic signatures was filed with AMREF ESRC and approved in December 2015. All participants signed an informed consent form in English before participation.

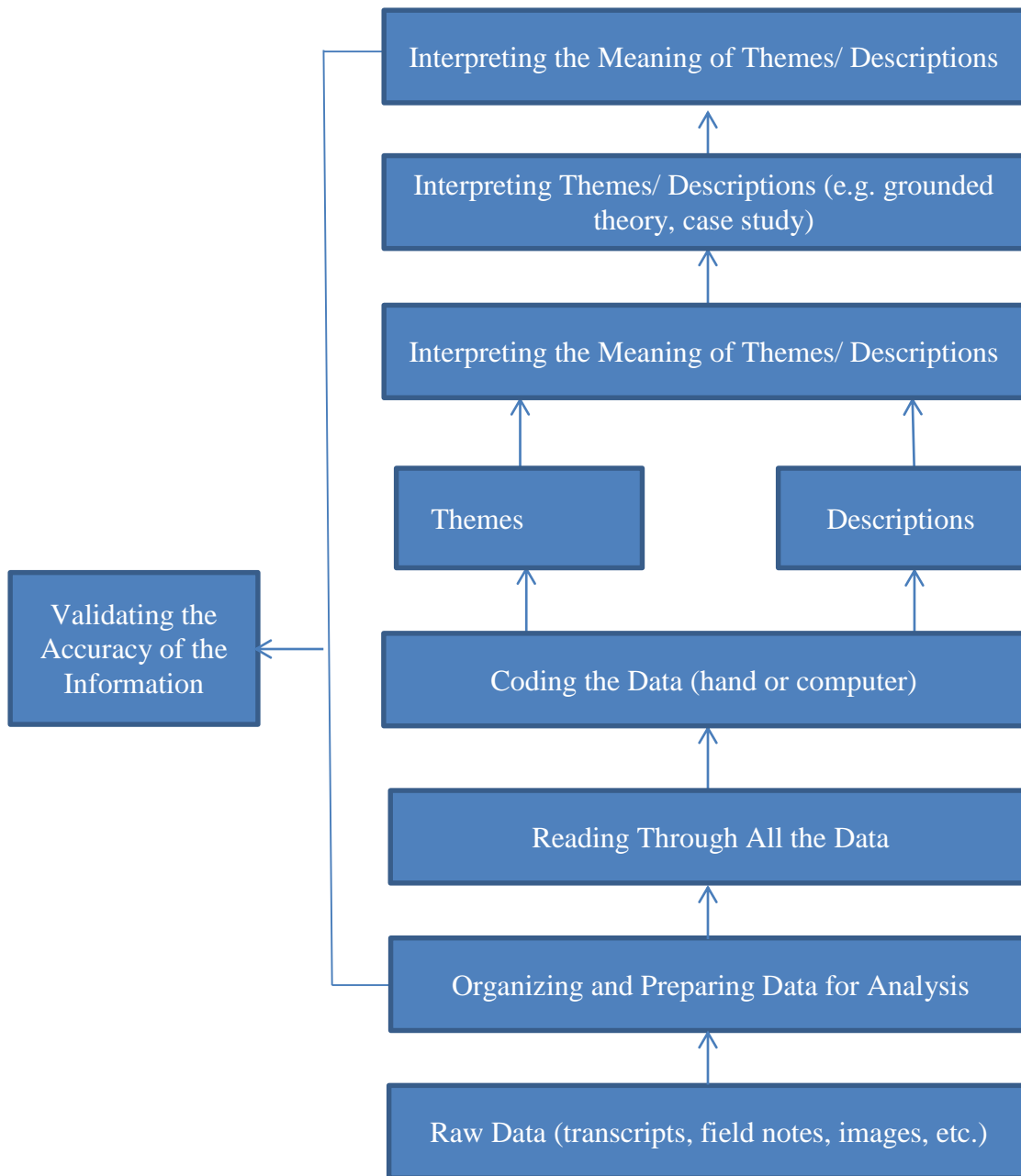


Figure 5. Steps in Data Collection and Analysis

CHAPTER 4: QUALITATIVE INTERVIEW RESULTS

This chapter reports the results of semi-structured interviews conducted with 13 of 20 possible participants in response to the three research questions and their related study aims. The objective of the interviews was to obtain their opinions on the barriers to cancer testing and treatment in Kenya.

Seven (n=7) of the participants were clinicians. These included three oncologists, two pathologists, one surgeon and one palliative care doctor performing surgery as part of cancer treatment. All but one of these seven practiced in the main cancer testing and treatment hospitals in Nairobi—KNH, Aga Khan Hospital, MP Shah’s Cancer Care, and Nairobi Hospital. One of the clinicians practiced in a mission hospital located in the outskirts of Nairobi.

Seven non-clinical cancer service providers (three male and four female) who were cancer support group leaders were interviewed. Most of them operated in Nairobi, however, each group conducted outreach services outside of Nairobi as a way to raise awareness about cancer and promote early detection. Table 2 below summarizes the characteristics of the study participants.

The interviews lasted between 25 and 35 minutes, with the shortest lasting 14 minutes and the longest 46 minutes. Each interview was recorded and audio files were transcribed. Participant responses to each question were grouped in two categories: NCP (non-clinical participants) and (CP) clinical participants.

Table 2. Characteristics of the Study Participants

Sample Size	Clinical Participants	Non-clinical Participants
Total n=17	7	7
Gender		
Male	3	3
Female	4	4
Average number of years practicing medicine	15- 27 years	N/A
Interview Locations (in Nairobi)		
Health Facility	4	2
Office	1	2
Other location - café, home	1	2
Telephone	1	2

4.1 Data Analysis

The content of each transcript was analyzed and codes/themes manually identified, based on the respondents' remarks. Common themes from the responses were identified and used to interpret the meaning of the responses.

A concept tracking table as shown below (Table 3) was used to organize and illustrate the relationship between the conceptual framework, research questions and the themes that emerged from the participants' response. Each of the five aspects of the framework were used to inform the study design, key informant interview questions, the analysis and presentation of results, and recommendations in the plan for change section.

Table 3. A Summary of the Emerging Themes Based on the Conceptual Framework and Research Questions

Framework Concepts: Characteristics of the Population at Risk and Consumer Satisfaction	
Research Question 1: What are the patient characteristics, including level of cancer awareness, among people seeking access to cancer testing and treatment services, and which of these are modifiable through policy or other actions?	
Emerging Themes	<ul style="list-style-type: none"> • Financial costs • Knowledge and information about cancer
Framework Concepts: Characteristics of the Health System Delivery and the Utilization of Health Services	
Research Question 2: How does the organization of health services and the health infrastructure affect access for patients?	
Emerging Themes	<ul style="list-style-type: none"> • Health-seeking behavior • Location of cancer diagnostic and treatment services • Patient follow-up and referral
Framework Concept: Health Policy Actions	
Research question 3: What policy actions can improve access to timely cancer testing and treatment in Kenya?	
Emerging Themes	<ul style="list-style-type: none"> • Policy development • Policy implementation

4.2 Key Findings

Five main themes emerged: 1) financing access to cancer testing and treatment; 2) level of knowledge and information; 3) the population's health-seeking behaviors; 4) locations of cancer diagnostic and treatment services and 5) policy development and implementation.

The participants' responses were analyzed under each theme and sub-category as presented in table 4 below.

Table 4. Themes and Sub-Categories from the Semi-Structured Interviews

Theme	Sub-categories
1. Financing cancer diagnostic testing and treatment is expensive and serves as a major barrier for patients seeking cancer services	a) Costs to access diagnostic services b) Treatment costs c) Post-treatment costs d) Other costs – transportation
2. Lack of knowledge and information about cancer and misinformation was common among patients and clinicians	a) Public health awareness about cancer b) Misinformation and myths c) Lack of accurate information by clinical providers d) Provider-to-patient communication
3. The populations' health-seeking behavior affects early detection and follow-up	a) Late presentation b) Lack of routine checkup and screenings c) Patient follow-up and referral
4. Location of cancer diagnostic and treatment services	a) Distances to services b) Lack of diagnostic and treatment skills and equipment
5. Policy development and implementation	a) Unavailability of cancer policies focused on the public's health

1. Financing cancer diagnostic testing and treatment is expensive and serves as a major barrier for patients seeking cancer services. The four main categories of cost are discussed below based on the participants' responses.

a) Costs to access screening and diagnostic services: Majority of the non-clinical participants (n=4) noted that screening tests for cervical and breast cancer were the most common and easily availed services to the public through organized cancer awareness and screening camps. This was due partly to the use of lower cost methods, such as the visual

inspection with ascetic acid for cervical cancer and the self-breast exam that women and clinicians can perform to detect breast anomalies before further diagnostic tests, such as mammograms, were performed. Some of the diagnostic tests such as mammograms were deemed expensive for the “average Kenyan.”

For cervical, hospitals charge KShs. 5,000-10,000 (US \$50 to \$100). Because what normally happens is with cervical there are some stages ... for you to properly diagnose, you'll need to do a pap smear, which is KShs 2,500 (US\$ 25) and above. Then beyond that, there are some other tests... Even to get a simple thing like a mammogram, it's very expensive... - NCP1

... Right from the start of course ... treatment and diagnosis is expensive and many people are unable to afford it. - NCP2

b) Treatment costs: Both clinicians and non-clinicians (n=11) cited treatment costs as the major barrier and first determinant of treatment for both insured and uninsured patients.

Costs were lower in the public hospital when compared to the private hospitals. The cost of cancer drugs was often cited as the main driver of the treatment costs.

Mostly financial constraints – that is the number-one constraint. Secondly the accessibility of medication because we have to import each and every medicine ... there are no oncology drugs produced in Kenya, so we have to get them from other countries like India and UK.- CP1

Definitely, money first and foremost is the major concern ... because, as you know, in our setup, you can't even access medical services... the major challenge (to treatment) is lack of financial ability. - NCP 4

Whether they've accepted to treatment after explanation on the side effect, is based on whether they can afford, which is actually number one ... - NCP 5

Two respondents mentioned that some patients preferred to seek treatment in India, which they deemed cheaper and more effective than getting treatment in Kenya. However, one of the participants was skeptical of the effectiveness of treatments in India due to the patients' lack of knowledge and understanding about cancer.

Those who believe that India is the only place they can get cured are usually encouraged by us to go because, with that mindset, they might blame you for not curing them when the reality is that that cancer cannot be cured ... They might say cost, but it is not much cheaper than treatment in Kenya. Maybe it can be cheaper than treatment in Europe and the States, but not here. It is more of a mindset. - CP4

Firstly, it is well-known that cancer treatment in Kenya is very expensive. So the first thing that comes to mind is where to go for treatment. India is a common destination, but it's not cheap so the next step is fundraisers for the same. But we try and sensitize them to the fact that there are viable treatment avenues within the country, which they should consider before looking at options abroad, which are also quite costly. - NCP1

c) Other costs – transportation: The concentration of oncology services in major towns posed an additional barrier for rural populations, as cited by some of the participants (n=5). People outside major towns incur additional costs associated with transportation and, in some cases, accommodations when traveling to the facilities that have cancer diagnostic and treatment services.

...And as you'd expect, most of the facilities are here in Nairobi and a bit in the other major centers: Mombasa, Kisumu, Eldoret. And that includes the doctors as well. So the rest of the country is really bare. And most of these services are in the private [sector], so they are really expensive. – NCP3

Cost is number one. Also availability when they are up-country. You know they have to travel to the district hospitals, which to some of them may be quite far. Then when it comes to the final treatments, they may have to come to Kenyatta, especially for the [radiation]. These days they have opened up when it comes to giving chemo in the outside towns and I'm sure you've come to hear of that ... I think the provincial hospitals are also administering chemo, but for [radiation], they still have to come to Kenyatta or the private hospitals in town. – NCP 5

d) Post-treatment costs: The cost of post-treatment drugs for prostate and breast cancer were deemed expensive and a barrier for patients who were unaware that they would require them in addition to regular check-ups with their doctors (n=3). Access to oncology services also affected post treatment patient follow-up.

.... Then the difficulty in following up patients, especially if they are coming from up-country [rural areas]. They are not keen on coming back to us for follow-up unless they develop any symptoms because of the logistics and transportation issues. - CP1

... Or even after you know that in the case of prostate cancer people have to go onto hormonal treatment for the rest of their lives and this can be expensive. But this has been one of the major challenges – the financial status. Right from the start of course the status of many Kenyans ... treatment and diagnosis is expensive and many people are unable to afford it. – NCP2

... The other was about finances because the treatment is very costly. Some of the ongoing drugs like Tamoxifen are very costly. – NCP6

Eleven of the 13 respondents cited patients' ability to afford cancer diagnosis and treatment service as the number-one determinant of whether they would undergo treatment or complete treatment, in some cases. Some patients were unaware that they would incur follow-up and post-treatment drugs. Services at public hospitals and outside of Kenya were deemed more affordable primarily due to the importation of cancer treatment drugs and taxes. Understanding the financial burden to patients at each phase could help the government institute policies that improve access to treatment and post-treatment therapy, when needed. Recommendations on this are further explained in the policy section.

2. Lack of knowledge and information about cancer and misinformation were common among patients and clinicians. This led to late presentation by patients and misdiagnosis by clinicians who lacked knowledge of cancer and its symptoms.

a) Public health awareness about cancer is low and affects patients' decision to seek cancer testing: According to most of the participants (n=6), the majority of patients did not know about cancer before their diagnosis. Some patients had general knowledge about cancer, but nothing specific about their type of cancer. This was attributed to a lack of awareness about the disease, in addition to other factors such as the patient's financial condition and literacy level.

Basic knowledge and lack of information, because there are many people living with half symptoms of this disease like blocked urinary tract, pains here and there and local dispensaries keep giving painkillers for such cases till it's too late. I think lack of awareness is to blame, so we encourage the group member to create awareness on cancer to as many people as possible Our primary objective is to try and encourage people to talk about it much more to the wider population – not only to those who have cancer. – NCP2

I think, first of all, literacy, knowledge. If they're not literate, they may not even know what it is. I have seen patients who have come to see the doctor with a huge fungating wound. So literacy, knowledge and culture are also very important and again funding. – CP3

Increasing awareness about cancer could improve patients' ability to seek screening and diagnostic services on time. Policy actions to improve public education through awareness campaigns was cited (n=5) as one of the factors to be considered in improving the current cancer Act.

It's difficult to say because the access to cancer screening and treatment is based on the awareness that the people have, accessibility to the facilities and availability of resources to ensure that they came for screening. – NCP7

There should be also increased advocacy to sensitize the public and increase awareness. – NCP1

I think awareness of both the disease and our services [affects patients' ability to access the facilities' services). – CP2

... there is very little awareness by the people – maybe just in the large urban centers and during the October awareness month. – CP6

The government needs to be very aggressive in creating awareness. Whether through the media like they did with AIDS or through NGOs to go out there to carry out the awareness and screenings and for people to be made aware that it is their right to seek these services when they enter government institutions. – NCP5

One participant reported that patients' lack of full disclosure of their symptoms to the doctors, and the stigma associated with cancer, as a contributing factor to misdiagnosis.

And if the patients are being waited for to come report their symptoms, they don't because of stigma and when they do they end up being treated for other things due to ignorance of the patients. They need to open up to the doctor on all issues that you

are going through so that he may deduce what you may be suffering from. And so the disease is left unattended because the patient has covered up. – NCP5

b) Misinformation and myths about cancer is affecting patients' decision to undertake treatment once a cancer diagnosis is made. Some of the patients had the wrong information about cancer. One respondent cited cultural and religious beliefs as rampant, in some cases, regardless of the patient's level of education.

... But because there's also this "witch" culture, they believe somebody has bewitched me and everything. – CP3

c) Lack of accurate information by clinical providers contributes to misdiagnosis and the high number of late presentations observed by a majority of the study participants.

A sub-set (n=2) of the cancer patient support and advocacy group leaders cited lack of knowledge by the clinicians as contributing factor to patient misdiagnosis and, in some cases, late presentation when the cancer was advanced.

We are also targeting health providers: dispensaries, hospitals because there is some negligence there because people keep going to hospitals and dispensaries and instead of getting proper diagnosis, they take you round and misdiagnosed until it's too late. – NCP2

Sometimes it [has] nothing to do with finances, but the doctors who misdiagnosed them. We have so many people being taken around in circles by the doctors – general practitioners who did not know that it was cancer. So many are complaining that if they knew earlier or were diagnosed earlier, their cancer would have been treated. You are told you have a sore throat and the doctor does not look at the issue keenly. – NCP6

d) Poor provider-to-patient communication is a determinant on treatment uptake, follow-up and patients' ability to understand their treatment and expected outcomes:

Participants (n=3) reported the manner in which the doctors communicated to patients about their cancer was in some cases a determinant on whether the patients would seek treatment. The use of clinical terms was not helpful in communicating with patients. One participant

noted the need to improve how they communicated with cancer patients and their families, especially when the disease was terminal.

The communication after the initial consultation with the health care worker when they are now being told of the situation and the advised treatment plan is critical. How this is communicated or received by the parent or patient determines whether they will either start on the regimen as prescribed or even whether they'll follow through with subsequent appointments. – NCP4

Not very much information is given to them, but a few years ago we wrote some communication on various cancers and were published by the Nairobi University Press. ... We used to keep them at the reception for patients to read and it would help because it would give them some level of understanding and made it easier to communicate with patients. – CP4

... around 20% to 30%, they usually will have an idea [about cancer]. For example, like when I was working at [name withheld] hospital, doctors will talk about a disease in front of the patient during the ward rounds and use the medical terminology and the patient wonders what were they talking about. So when the patient comes to the hospital, they say the doctor kept on talking about 'Carcinoma.' So when you ask them do you know what it is, they say no and then you have to start telling them what it is. But in the back of their mind, I believe they can read the expression on the physicians face and everything. The fact that they are willing to talk about it, or they had a neighbor who had something on their breast and it was cancer. They kind of guess[ing] sometimes, but in terms of giving the full diagnosis to patients, we're not doing very well. – CP3

One respondent noted that doctors need to improve their communication with patients, regardless of the patient's literacy level. This suggest a discriminatory practice by doctors based on a patient's ability to engage with a physician.

Well, I think you know in Africa a doctor is a god. What the doctor says is what goes ... If you're going to give them chemotherapy, you need to tell them what it is, what it is going to do to their body. But unfortunately people don't do these things ... especially if a patient is illiterate, it's assumed that they don't need to be told anything. But an illiterate patient is going to suffer the same side effects as the literate one. So it's good to tell them when you're treating them. – CP3

These finding suggest the lack of general information about cancer affects the patients' decision to seek cancer diagnosis and treatment services. Respondents (n=3) cited the need for public awareness and education to increase national awareness about cancer.

Additionally, patients need to be encouraged to disclose symptoms to doctors to increase diagnosis accuracy. The doctors communication with patients as reported by participants (n=2) indicates the need for patient-centered communication due to its impact on the patient's treatment decisions, compliance to phamarco-therapies and, the patients' subsequent health behavior if changes are needed ⁵¹. Communication to the patient and their family member(s) or caregiver(s) was cited as a primary practice by the clinical participants in deciding the patient's treatment. A greater awareness by the clinicians on the impact of their communication approach on the health-seeking behaviors of the family members can improve the timeliness with which any family members at risk can seek diagnostic services.

3. The populations' health-seeking behavior influences the use of screening, diagnostic and post-treatment follow-up services and leads to late presentation of cases among the Kenyan population.

a) Late presentation is a major barrier to effective treatment: Participants (n=6) reported that the majority of the cases sought medical care when symptoms were present. In addition to the lack of information about cancer symptoms, there is a significant fear of cancer due to its association with death. As such, the majority of the cases were presented to the doctors when the cancer had advanced and treatment outcomes were poor.

... two is the stigma of cancer. People do not want to know about it and the expenses involved, especially for those who come in stage 3 and 4. – CP2

People will die but no one will say they died of cancer. They are very scared of the word and people want to hide it as a cause of death. – NCP2

Unfortunately, most cancers we're finding are in the late stages. Stage 3 [and] 4. This is why we advocate for people to be aware and seek annual screening ... We realize that the medical personnel are really stretched. – NCP 3

Again most of the diagnosis is done at stage 3, 4 or 5. Patients will wait, not necessarily wait, but are ignorant or they may come early and the doctor isn't doing

the right thing. They complain of abdominal pain, burning sensation, then they're treated for ulcers or amoeba, yet they have a tumor growing. So it maybe late diagnosis and late treatment that result in the patient coming when it's quite late.
– CP3

It depends with the type of cancer, if it is breast cancer in Nairobi, we are seeing stage 2 and 3, advanced. We are getting smaller percentages, but from up-country, we are getting more advanced cases. ... Prostate cancer seems to be advanced cases. Cervical cancer, we see a few, but they are mostly advanced cases. – CP4

For breast cancer, I could say 50% to 60% of my cases come in at stage 3. I would say overall, 70% to 80% come in late at stage 3 and 4 of the disease. – CP5

b) Lack of routine checkup and screenings: Access to routine health screenings that can detect cancer at early stages is limited by the financial costs associated with checkups, as well as the fear and stigma associated with cancer, as noted by some of the cancer patient support and advocacy group leaders (n=2).

In fact, most people don't even go for basics like screening because they can't afford it. So money is the biggest problem. Some people are even scared to address it, but by the time they are coming to our camp, it is like they are braver than the average person because they know that it is possible. – NCP3

For the people in our groups, I can say 70% of the cases went to the doctors when the cancer was advanced mostly with the cervical cancer cases. I can say that it also has to do with their economic situation because those who have money go for annual checkups and whereby the prostate cancer can be diagnosed early, but for those who do not have funds ... they come when it is late stage. – NCP6

However, most (n=5) of the patient support and advocacy groups engage in screenings, primarily for prostate, cervical and breast cancer, and in rural areas where cancer screening services and skills are scarce. Attendees' ages vary, but that does seem to influence the decision to attend the cancer screening sessions. Additionally, the availability of low-cost screening methods for breast and cervical cancer encourages screening for these two cancers. These groups partner with hospitals and trained clinicians to conduct the screening. This approach allows for patient registration and follow-up if needed.

...we screen people between the ages of 17 to 60. We emphasize on screening people outside the metropolitan or urban areas. We focus on the most common cancers we have ... the reproductive cancers – that is breast, cervical and prostate cancer. ... What we do is instead of holding these screenings in the hospitals, we usually hold them in schools, churches, open grounds ... so once they come and we have them screened and diagnosed, then we have a very good referral process to various hospitals – like here in Nairobi, we usually send them to Kenyatta. – NCP1

... We have patients who came to us from our screening programs and they are from rural and peri-urban. Their education level ranges from basic informal education and their age ranging from 21 years to our oldest lady who was 73 years old. ... We provide awareness about cancer and the benefits of early detection. We also provide outdoor screening services in the villages and provide information on what the diagnosis means and why they need treatment and put them on a referral system where the doctors provide information on the treatment plan that they could undertake. We also [provide] information of what is available in terms of treatment on other institutions and take them through the costs. – NCP7

One participant also cited that patients sought screening only once symptoms manifested themselves.

Most people don't just go for screening even after the awareness. They usually come for screening once they get a symptom. – NCP1

The American Cancer Society provides guidelines on the frequency of screening for breast, cervical, colorectal, prostate cancers and general cancer checkups⁵². Understanding the health-seeking behaviors of Kenyans is important in designing cancer education and information strategies that will improve patient and provider initiated cancer screening. Financing screenings as part of primary healthcare services could be one way of reducing the financial barriers that deter Kenyans from seeking early screening and some of the more expensive cancer diagnostic tests, such as mammograms.

4. The availability of cancer diagnostic and treatment services are one of the main barriers faced by participants. Long distances to services located mostly in urban areas are difficult to access for rural populations. Participants called for the decentralization of these services. Additionally, under-equipped facilities and personnel compound the challenge of accessing these limited services.

a) Long distances to cancer testing and treatment centers cause patients additional duress. Some (n=5) of the participants reported that the current centralization of cancer diagnosis and treatment services in Nairobi poses a significant challenge for populations outside of the city. Some of the county, mission and private hospitals can conduct surgery and administer chemotherapy for cancer patients, however, they lack radiation facilities and have to send those patients to Nairobi. The long distances affect patient compliance to treatment and follow-up with doctors.

... even if a patient has the ability to access these services, you find that they again have to travel long distances just to reach these said services. For instance, we only have three public hospitals that provide childhood cancer care: Kenyatta, MTRH & New Nyanza. To some extent, Coast General, but that one is on and off, so it's yet to be established. Out of these, only MTRH and Kenyatta are the ones I'd say that are fully functional. That means that for the 40 million Kenyans, people have to travel to those three centers, with the exception of those who can afford private hospitals.
– NCP4

Thirdly, the resources are centralized. Like the radiation machines are here in Nairobi. ... There is no availability for such kind of things. ... We need to decentralize the treatment centers, get more radiotherapy machines and train people to improve service delivery. There is only one radiotherapy machine in the public sector. – CP1

... Of course the treatment centers, as I had said earlier on, need to be decentralized again. So that we have not just KNH with a radiotherapy machine, we need to have one in Kisumu; we need to have one in Coast so that those people can access treatment nearer home. – CP3

Some participants (n=3) recognized government efforts to address equipment and personnel shortages though these efforts were taking long to materialize.

In the last couple of years, the government released money to buy equipment for the counties. This is an ongoing process, but you send equipment to the county, but there [is] no technician to run the machine. So everything takes a long while. It means the universities need to train the personnel. They then need to be deployed all over the country and all that takes a while. – NCP3

The government is also looking at establishing four centers of excellence for cancer care so how has that evolved? Where is it in terms of planning? How is it being financed? Because we can't have cancer centers in all 47 counties, because it's not feasible. Currently we have five MRI machines within a radius of 10 km in Nairobi and only one is over utilized, which makes it break down almost daily. Whereas, across the road at Nairobi Hospital, it only runs for two hours a day, while the one in MP Shah works for one hour a day. While it costs millions to buy, down the road from there – about 2 km at Aga Khan – they have comprehensive cancer center and their machine is idle 60% of the time. – CP5

... I'd like to see a deliberate effort in the Act towards the provision not only of equipment and facilities, but in personnel, because we may have all these facilities and equipment but no trained personnel to match. – NCP4

b) Lack of skilled personnel and equipment affects delivery of cancer services to

patients, results in long wait times and high provider-to-patient ratios. The lack of additional equipment, mostly radiotherapy machines in public hospitals, was reported by respondents (n=3) to result in long wait times and a sense of hopelessness even among the clinicians. Costs at private facilities are prohibitive for the majority of patients, resulting in the underutilization of the radiotherapy machines available in private hospitals. A sub-set of the participants reported that the government has negotiated with some of the private hospitals to treat urgent cancer cases, although the criteria for determining these cases was unclear.

Shortage of radiation machines in particular is a big challenge because, once you refer someone, there is not much you can do but just wait and hope for the best. But you encourage those who can afford to go to the private facilities, which are running below their capacity because patients cannot afford to go there. We need radiation machines outside Nairobi, also in Kisumu, Mombasa, Nyeri and the like. – CP4

Like the level 4, level 5 hospitals, they need to be equipped with the cancer screening kits. Because I think in Kenya we only have two referral hospitals: Kenyatta and Rift

Valley Hospital. Those are the only ones dealing with cancer. Those level 4 and 5 hospitals, they are there in nearly all the counties, but they don't have even the personnel, let alone the kits. – NCP1

One, many people believe we don't have enough expertise. Two is the machines. We may have the machines, but we don't have the personnel to operate them. Then, those hospitals that have them, it's very, very expensive. Even to get a simple thing like a mammogram, it's very expensive. – NCP1

Three participants cited the need to train health personnel to deliver cancer services.

They need to train the medics that when a patient comes in, because this thing is so prevalent, let's ask the patient to guide us to know if they may be suffering from this ... Also at the training level of these nurses. For instance, I have breast models and most of the times, we are the ones showing them what to check for. So I think it is not well covered. – NCP5

The other challenge we have is healthcare professionals who are not well-trained to handle cancer patients. We have I think only two trained oncology nurses as you might have heard. Maybe, we have less than 11 or 12 oncologists. We don't have enough human resource[s], enough experts in the field. – CP3

How many oncologists are here in Kenya? There is no master's training program in oncology here in Kenya. Now they are starting a master's training oncology [program], but when these students graduate ... where are the machines? – CP1

Participants reported the long wait times to see a doctor as additional barrier to treatment. Practitioners (n=4) reported an average wait time by patients of 1 hour, with the shortest being 5 minutes and the longest 6 hours, in the public hospital (KNH). Additionally, oncologists relied on non-oncology personnel to assist in carrying out oncology services.

In a public hospital like Kenyatta, they can wait for as long as 6 hours, but in the private practice most people make appointments so you see them in good time. – CP4

It really depends on the number of patients, but it may range anywhere between 5 minutes to 5 hours, depending on the time a patient got to the hospital, mainly because it's a first-come, first-serve basis. – CP6

We use the non-oncology nurses – that is one area we need to train for and also the oncologists are very few in this country. We have around eight medical oncologists in the country, about seven radiation oncologists, surgical are about two, pediatric oncology we have one or two, laboratory base hematology who practice oncology around eight, gynae-oncologists maybe four or five, those who are trained on both

chemo and radio clinical oncologist around five. Pathologists who do serious cancer work are also few. – CP4

One participant cited the lack of a tumor board as barrier faced by oncologists when deciding a patient's course of treatment based on diagnostic test results. One participant reported having to rely on consultations with other oncologists in his professional network to determine the best course of treatment for a patient.

We need to have [a] tumor board to support my work with the surgical oncologist, medical oncologist, pathological oncologists. ... So we have to take the decisions by ourselves because there is no tumor board. Without the support of other specialists, some of the work faces hurdles. I have access to a virtual tumor board using my iPhone. ... I have access to colleagues in other countries through a WhatsApp group. I put up my question and the group members discuss. After two or three days, we arrive at a decision. – CP1

The majority of respondents agreed that if the country is going to address the current shortage of qualified personnel to handle the volume of cancer cases, it must invest in trained oncology personnel. Simultaneous investment into equipment and personnel will reduce the burden placed on the main public hospital (KNH) that serves as a national referral hospital for most patients.

The under-utilization of cancer services in the private facilities is primarily tied to costs, which are deemed expensive by the majority of patients. Participants would like to see more public-private partnerships on behalf of patients who cannot afford treatment at private hospitals so they can access the therapies they need, such as radiation.

The availability of one radiotherapy machine in the public hospital is a major area of concern cited by the participants. It limits timely access to treatment for patients and reduces the chances of better outcomes since patients have to wait on average for six months, if not longer, due to the high volume of patients and the machine's frequent breakdowns.

5. Policy development and implementation.

One section of the semi-structured key informant interviews sought the opinions of participants on the current cancer Act and its effect on patients and providers in the cancer sector. Each of the respondents provided their opinions and recommendations on how it could be improved to respond to the current barriers. Some of the participants (n=3) stated that the Act was not perfect and that it needed to be implemented in its current state before any amendments were made. A second group (n=4) stated that the Act was an administrative tool and needed to be revised to be more public facing and responsive to the barriers facing patients and providers. A third group (n=3) stated that it had no impact on their practices.

Three main themes developed from the analysis of the participants' responses:

1). Financing cancer diagnosis and treatment; 2) Decentralization of cancer services – this focused on developing a cancer health infrastructure that includes equipment and trained personnel at the county level; 3) Creating an Act that addresses cancer as a public health issue. The Act would include a government plan to raise awareness of cancer as a significant public health issue and remove barriers that result in delayed diagnoses and poor patient outcomes.

Key policy findings

1. The 2012 cancer Act has had some effect, however, it needs to be revised to respond to challenges faced by patients seeking treatment.

Participant were divided on whether the cancer Act has made any impact on improving access to cancer testing and treatment. Most participants stated that the Act was an administrative tool created to help establish a government body to address cancer and

provide guidelines for doctors treating cancer. That has not yet been implemented. One participant was hopeful that the government would implement it in future.

I think it's more ... administrative. It needs to include more of clinical staffing. It's more of a National Cancer Institute, The Board, they'll do this and that. That's important, but there's so much of that in it that we forget the other part ... so I think it would have benefit if we had put more practical clinical issues on access to treatment, access to palliative care, access to radiotherapy, and also education on awareness. It is there, but I think a little more emphasis would help. Because I think the first few pages are just ... with the NCI, the board, etc. – CP3

The Act is one thing. Rolling it out is another. – NCP3

It is still a long way behind. I wish I had my laptop. I [would] show you the data I have. We have gone round and round and round, and I have never seen government people carrying out campaigns like they used to do for AIDS. – NCP5

The policy has not done much because, to be honest, it is just a policy – that's it. The actualization hasn't really happened in the country. I have heard from the patients. I know that there is a plan to have cancer centers in each county. But right now, the Act hasn't done much. It is just a policy. – NCP6

I saw the draft of the Act, but I don't think it has made any impact on access to cancer treatment. However, some awareness has been created in the last few years due to the Act through the momentum that was given to the field of cancer because of the personal problems faced by the ministers and support from the media. So far the situation has improved, but I really doubt that the government protocols and policies have made any impact. – CP1

A subset of the participants stated that the private sector (civil society organizations) were implementing the Act on behalf of the government.

I feel that the government isn't doing enough towards implementing it. There are a few things from the government which are encouraging ... but in essence the Act has not been implemented. If anything it is us, the private sector, who are trying to implement what we can, but we are hopeful for the future. – CP1

I don't think much has changed and I think cancer services in this country are being run by the private sector and hospitals, like Kenyatta. The rest of the policy just dictates how hospitals run their services and not cancer specifically. – CP4

No, it is very rudimentary in the country and there is very little awareness by the people – maybe just in the large urban centers and during the October awareness month. – CP6

Some (n=4) stated that the Act could be implemented and later amended.

The Act is okay. It just needs to be implemented with urgency. – NCP3

I think coming up with policies is good, but if there is no impetus to actualize it ... put it into action, then there is no need to come up with them... We have so many policies and guidelines, but they have never been implemented. ... The government needs to stop making too many policies and first try to work with the policies that have been developed. – NCP5

I think we should first implement as it is to feel the impact, then improve from there because a lot of work went into it. – CP2

One participant stated the need for a new Act altogether that would be public health friendly and able to reach the grassroots. Additionally, some of the participants communicated the need for a sense of urgency to be stated in the Act – such as the urgency created in response to the HIV/AIDS epidemic.

We need a different Act altogether all in the sphere of public health and public health awareness, not one that tells doctors the protocols and the procedures of dealing with the disease, and not one that talks about collecting statistics. That is all good and important ... and there are some people doing a great job with the cancer registry ... but the Act is too weak in my opinion. We have to look for one that is more public health oriented and talks about public information. ... We need what was done with HIV in Kenya, which incorporated maternal healthcare and people had to be screened for AIDS. ... There must be a way to do this for cancer with a very definite aim of reaching the grassroots. – NCP2

2. Policies can be improved to address the financial barriers caused by treatment costs.

Participants cited drug costs as one of the major determinants of treatment uptake and compliance. Improvements to the Act, as cited by participants, could address the fear and stigma associated with cancer.

a) Cancer treatment drug costs are expensive and a significant barrier to treatment.

Three participants cited the need for a policy change on cancer drugs taxation. They indicated the government's need to remove taxes on cancer drugs, or subsidize them to make the drugs affordable or free. Participants often cited the removal of taxes on drugs to treat

HIV/AIDS and the subsequent ease of access to treatment for HIV/AIDS patients as an example of how removing taxes on cancer drugs could affect patients' access to treatment.

Subsidizing the cost of cancer treatment and all that comes with it, i.e. the cost of drugs, etc. Cancer drugs should be tax free just the way they uplifted the HIV drugs, which are very cheap and readily available in all major hospitals. – NCP1

For the patients ... if the policies are going to affect their lives ... they want to know if the taxes on the cancer drugs like Tamoxifen are going to be removed. The policies have to be felt by the patients, like reducing the tax on medication so that the prices can drop ... like in India where the same drug can be half the price, we get it here in Kenya. The policies are good but the government can do something like this (removing taxes on drugs) that can affect the people's lives directly. – NCP6

b) The Act needs to address challenges faced by cancer patients when seeking coverage for cancer diagnosis and treatment from private insurance providers. A subset of participants cited discriminatory practices by insurance companies once they are diagnosed with cancer and are seeking treatment.

Insurance companies are not really doing cancer ... If you get cancer, most of them don't want to take it up because it's really expensive. If you're still under the cover, they may do the first course of treatment, then after that they start giving you letters that they can't take it up. – CP3

The insurance should be cancer friendly, that is NHIF, then the other insurances so that they can cover those who need services. – CP4

c) Insurance through NHIF provided limited coverage to patients despite recent statements by the NHIF authorities that NHIF would pay for cancer treatment. Some (n=4) of the participants cited lack of clarity on which treatment costs the NHIF covers. One cited that NHIF provided coverage for patients seeking treatment in India, but not in Kenya.

I think the government is trying to see if they can have NHIF include cancer. I think there's some progress there. There is some conversation there, but I don't know how far they've gone. – CP3

NHIF is covering cancer treatment, but they aren't making noise about it. So most people don't know they can go to NHIF to cover them or even cover their treatment abroad. ... NHIF [is] not disseminating information. And then there are those small

clauses; you need to be 100% contributor; okay, who is that? Civil servants, public servants? What does that really mean? There needs to be a whole education on that so that when you're paying your NHIF, you know what it covers and what it doesn't. – NCP3

We need to look at including free healthcare and treatment for cancer patients so that it provides a basis say for the workings with the NHIF for instance or any other institution that we may deal with. – NCP4

They are currently working on it, but they are already covering (cancer) to some extent, but there have been talks of them expanding the cover. It is not yet streamlined to clarify the exact cover one can get. – CP5

Participants cited the discriminatory practices of private insurance and the lack of clarity from the public insurance (NHIF) as an additional barrier that patients must deal with when seeking treatment. All 14 respondents were dissatisfied with insurance providers' practices. Some called for legislative action to mandate the insurers to pay for cancer treatment.

Key Finding 2: Better policies addressing Kenya's health system deficits – lack of equipment, skilled personnel and affordable drugs – are needed. This includes cancer policies at the county level and national policies.

Health facilities can improve the delivery of cancer diagnosis and treatment services through better public-private partnerships and equipping facilities with machines, personnel and drugs to treat cancer.

Even when we discuss private public partnerships with the government, it is very difficult. It is very difficult even when they agree for patients under NHIF to receive treatment here, they [the government] refuse to pay. It is very difficult. – CP1

We would like to disseminate the cancer guidelines to the county level, the common person so that when you go to hospital someone can easily look at the guidelines, look at your symptoms and grade you and, if you have cancer refer, you to the next level. – CP2

They need to have special cancer facilities and there is a plan to have four or five of those in the country, but it's yet to happen. Where patients can get treated by people who know what they're doing and with backup in terms of equipment, practitioners.
– CP6

Key Finding 3: Decentralization of cancer diagnosis and treatment to the county levels is needed to effectively address long patient wait times at the main referral hospital-KNH.

Decentralization of cancer services was cited by participants as one of the solutions to current cancer treatment costs and delays accessing treatment. As part of decentralizing cancer services, the government needs to disseminate current cancer diagnosis and treatment guidelines, which could help health personnel at the county levels screen and diagnose patients for cancer.

We need to decentralize the treatment centers, get more radiotherapy machines and train people to improve service delivery. – CP1

I think there's a move to decentralizing cancer treatment so that we have at least five major hospitals to treat cancer. ... So we now have Coast General Hospital, which has an oncology unit, Nyeri, and I think they're planning to start in Kisumu. Although we have these places, they don't have radiotherapy... but at least there's some starting point. – CP3

We also need to decentralize healthcare and take it to all corners of the country.
– CP4

I think a lot has changed since it was made because one ministry was in charge of everything and now things have been devolved to the counties, bringing a huge disconnect and a lot of tension. So we need to translate it to counties so as to empower the counties to own it and develop programs at their level – because of the different needs from county to county. – CP5

So I think that is very important, but I also think that the government should put possible facilities near to patients. For example, there should be a nurse who can do a clinical breast examination; there should be a nurse who can do a pap smear and if it's in the early stages, who can do cryotherapy. Those simple things that can be done at the community level should be facilitated so that we reduce, even at the community level, the incidence of cancer. But of course the treatment centers, as I had said earlier on, need to be decentralized again. So that we have not just KNH with a

radiotherapy machine. We need to have one in Kisumu; we need to have one in Coast so that those people can access treatment nearer home. We may not be able to do all these things across the country. There's nowhere in the country where they have all the things [because] it's expensive, but if we can have more than one public service.
– CP3

Participants had mixed opinions about the effects of the current cancer Act on patients' ability to access treatment. Majority stated that the existence of the Act since 2012 had raised the government's level of awareness about the increase in cancer cases and enabled the private sector [civil society] to validate the concerns that they had been raising about the surge in cancer cases in the county.

Some of the participants cited the need for the cancer Act to be revised to address the cost factor cited as the major barrier and determinant of treatment uptake by patients. Participants cited the need for the government to intervene and protect patients against discriminatory practices by the insurance providers, including the lack of clarity on patient coverage by NHIF.

Some participants reported the need for better stakeholder involvement in formulating policies governing the cancer sector, such as the cancer Act. Private sector oncologists stated that the Act applied to the public hospitals and therefore did not affect their practices.

The need to address the lack of resources – equipment and qualified personnel – was also cited as major challenges faced by cancer patients and oncologists. Overall, the majority of participants cited the need to avail services closer to the populations through the counties through the decentralized health system created by the 2010 revised constitution.

CHAPTER 5: POLICY ANALYSIS

This policy review is conducted under the policy aspect of the Andersen and Aday Framework that has been selected to guide this study's approach in responding to the overarching research question: *"How Can Access to Cancer Testing and Treatment Be Improved in Kenya?"* The review is also conducted to respond to research question 3: *What policy actions can improve access to timely cancer testing and treatment in Kenya?* And the corresponding Aim: *"To identify potential policy level actions that could be recommended to the legislature in order to improve access and delivery of cancer testing and treatment services in Kenya by integrating results of the qualitative interview with a policy review."*

In this study, policies are defined as the set of actions and ideas agreed upon by a group of people⁵³, in this case the government of Kenya, national and international stakeholders in response to the prevention and control of cancer in Kenya. These documents are recognized as official government positions on actions that can be taken by qualified individuals and stakeholders as part of implementing the actions or ideas presented in these documents.

Below is schema (figure 6) representing Kenya's cancer policy journey since 2011 to date, and some of the main documents that have been developed to guide delivery of cancer services in Kenya.

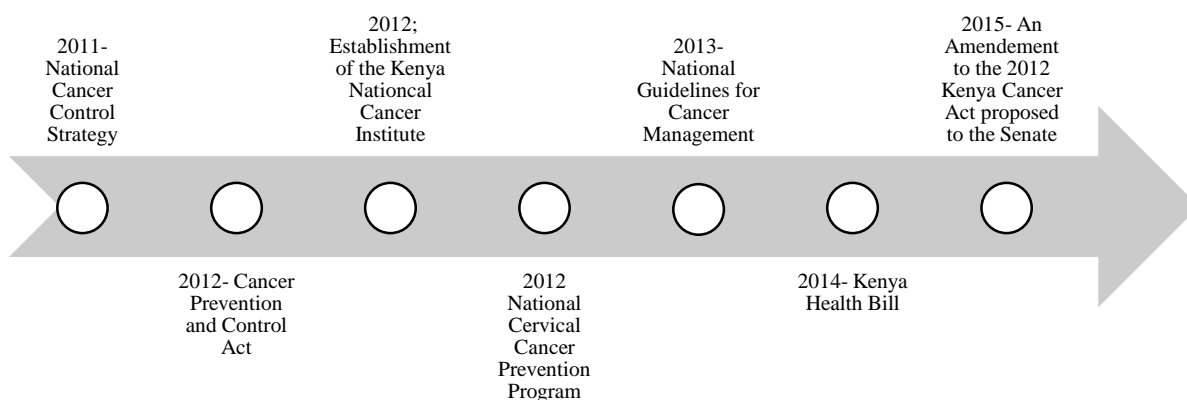


Figure 6. Development of Cancer Policy since 2011 in Kenya

Over the past five years, the Kenyan government, in partnership with national and international stakeholders, developed several documents to guide the prevention and control of cancer in Kenya. These documents (presented in Table 5 below) are referred to in this study as policies and guidelines. They are designed to respond to the need for accurate information on cancer, diagnosis and treatment protocols and to identify the human and infrastructural resource levels required to adequately respond to the demand for cancer services.

The creation of Kenya's Cancer Prevention and Control Act in 2012 laid the framework for the establishment of a national cancer registry. Since 2012, several guidelines on cancer prevention, diagnosis and treatment have been compiled by clinicians and civil society stakeholders in Kenya (see Table 5: A List of Kenya's cancer policies and guidelines). It is worth noting that there is remarkable progress in raising awareness about cancer throughout the country, however, these efforts are led by the private sector, non-governmental organizations and, in some areas, by the county level governments. The establishment of Kenya's National Cancer Institute is a second indicator of progress towards

creating a national office to manage information and action taken toward cancer prevention, treatment and control.

Table 5. A List of Kenya's Cancer Policies and Guidelines

Document	Objective
1. The Cancer Prevention and Control Act, 2012 (No. 15 of 2012). The National Council for Law Reporting with the Authority of the Attorney-General. 2012 ¹⁸	To create a legal framework for the development of cancer prevention, treatment and control interventions; and to define the role of the national and county governments in delivering these services.
2. The Cancer Prevention and Control (Amendment) Bill, 2015: An amendment to the Cancer Act (2012) ¹⁹	To clarify roles and responsibilities of the National Cancer Institute and the county level functions in the delivery of cancer services.
3. National Cancer Control Strategy. 2011-2016 ⁵⁴ -Government of Kenya Ministry of Public Health and Sanitation and Ministry of Medical Services, 2011.	An outline of interventions to be undertaken by the government and other partners to enhance existing structures and pull together additional resources to address cancer in Kenya.
4. National Guidelines for Cancer Management Kenya; August 2013 ⁵⁵	A detailed guideline for clinicians delivering cancer screening, diagnostic and treatment services for more than 20 types of cancer in Kenya. This guideline provides cancer staging guidelines, treatment modalities and lists potential drugs that can be administered for the particular cancer.
5. National Guidelines for the Prevention and Management of Cervical, Breast and Prostate Cancer. January 2012 ⁵⁶	Treatment and palliative guidelines for clinicians delivering cancer services – screening, diagnosis and management of cervical, breast and prostate cancers in Kenya.
6. National Cervical Cancer Prevention Program: Strategic Plan 2012-2015 ⁵⁷	A strategic framework and priority actions for cervical cancer prevention with the aim of reducing the incidence of cervical cancer in Kenya.
7. National Palliative Care Guidelines. 2013. MOH ⁵⁸	The guideline identifies key areas and suggests interventions to promote provision of holistic quality palliative care in Kenya. ⁵⁸
8. The Kenya National Patients' Rights Charter: 2013. MOH ⁵⁹	Guidelines to inform patients about their rights and responsibilities when seeking quality healthcare services; also serves as a conflict resolution guideline for patients and healthcare providers.

As a result of the above cited developments, Kenya's cancer service delivery sector is guided by the following three main policy documents.

1. The Kenya Cancer Strategy 2011-2016 ⁵⁴, which advocates for increased investments for the provision of cancer services in Kenya
2. The Kenya Cancer Prevention and Control Act, 2012 ¹⁸, which establishes the National Cancer Institute's (NCI) office and for the prevention and control of cancer in Kenya. In 2015, this Act was amended to establish the NCI's headquarters in Nairobi and to add the County Cancer Prevention and Control Committees. It is now cited as the Cancer Prevention and Control (Amendment) Act, 2015 ¹⁹.
3. The National Guidelines for Cancer Management Kenya (2013) ⁵⁵, which provides cancer service providers with treatment procedures, qualities and standards.

The other policy documents listed in the above table serve as auxiliary guidelines on the diagnosis, prevention, control and treatment of specific cancers in addition to the above three primary policy documents. Additionally, the overarching Kenya Health Policy, 2012-2030 ⁶⁰, whose objectives include reducing the incidence of non-communicable diseases such as cancer to levels below public health importance ⁵⁵, further strengthens the health framework's response to cancer prevention and control in Kenya.

An analysis of these three policy documents indicates steps taken by Kenya's government and stakeholders in response to the increased demand for cancer diagnostic and treatment services. Each policy document has clear objectives and activities to achieve the objectives as shown below.

- a) **National Cancer Control Strategy:** Created in 2011, the National Cancer Control Strategy was one of the early official government recognitions of cancer as a disease

of significant public health concern. It listed several objectives, including increased cancer surveillance, the need for investments into Kenya's health infrastructure, cancer research and personnel training, and making cancer treatment and palliative care drugs available for cancer patients. Primarily targeting medical practitioners involved in cancer diagnosis and treatment and policy makers, the strategy outlined interventions that could be carried out to achieve objectives outlined therein. Some of interventions include the control of biologic agents that cause cancer through vaccination, such as the HPV vaccine against cervical cancer; tobacco cessation programs, environmental control of carcinogenic pollutants, increased early detection of cancers and strengthening the diagnostic and treatment services. The strategy contains an implementation framework further outlining interventions, timelines and the roles of various stakeholders over a five-year period (2011-2016). Additional guidelines outlining interventions based on the type of cancer have been developed, applying the priorities set out in this strategy document.

- b) The Cancer Act, 2012:** Established through an act of parliament in 2012, the cancer act sets the legal framework for the establishment of a national body – the Kenya National Cancer Institute – to oversee and coordinate the efforts of stakeholders providing cancer treatment and diagnostic services in the country. In addition to the administration of cancer services, the act includes two parts that focus on the population: 1) part IV – Discriminatory Practices – this section states the rights of cancer patients and the obligation of entities to render services to cancer patients in a non-discriminatory manner and 2) part V – Education and Information – this part states the responsibilities of the government and the KNCI in the provision of cancer

information and education to the population. In 2015, the 2012 cancer act was amended to establish the headquarters of the KNCI in Nairobi and to establish County Cancer Prevention and Control Committees. The proposed amendments to the cancer Act (2015) provide legislative authority to county level policy formulation. The county level cancer prevention and control committee are part of the county level health committee. Members in the proposed cancer amendment Act (2015) include:

- A chairperson appointed by the governor
- A secretary to the executive committee elected by the member responsible for health
- One woman and one man nominated by the Kenya National Cancer Institute
- One woman and one man appointed by the county governor to represent special interests within the country

These amendments give responsibilities for cancer prevention and control at the county level to the committees, with the KNCI remaining the overall coordinating body.

- c) **The National Guidelines for Cancer Management in Kenya:** Established in 2013 these guidelines expanded on the National Guidelines for the Prevention and Management of Cervical, Breast and Prostate Cancer (2012). They also build upon the National Health Policy Framework, 2013-2030, the National Clinical Management and Referral Guidelines Volume III and the Cancer Control Strategy 2011 – 2016⁷. Targeting clinicians, it contains site-specific guidelines on the epidemiology, diagnosis, staging, treatment and prognosis of the majority of adult and pediatric cancers⁷. In addition, a chapter on cancer patient and support care is included⁵⁸. This

document has enabled stakeholders to further develop detailed guidelines for diagnosis and treatment of the three most prevalent reproductive organ cancers: prostate, breast and cervical.

Together these three documents dictate the current cancer services delivered in the country. However, without additional financial resources to implement the actions listed in these three policy documents, most patients are unable to access the diagnosis and treatment services listed.

CHAPTER 6: DISCUSSION

6.1 Application of the Conceptual Framework

This study's main objective was to identify barriers faced by patients seeking access to cancer testing and treatment, and barriers faced by providers delivering these services, with the aim of proposing actions to improve access to cancer diagnosis and treatment services to Kenya's population.

The Andersen and Aday Conceptual Framework on Health Access ¹ was adapted to guide this study and enable a better synthesis of information at each research phase. Using three approaches – a systematic literature review, a semi-structured key informant survey and a policy review – this study responded to the overarching research question: “How can Access to Cancer Diagnosis and Treatment be Improved in Kenya?” Three research questions were linked to each of the three approaches to enable a better analysis of information. Findings were applied in the implementation recommendation section and plan for change.

6.2 Study Limitations

This study recognizes the use of a limited subset of the population to provide opinions to inform recommendations. The generalizability of the interview responses is limited by the small sample size (N=14).

Due to the significant barriers and delays of obtaining ethical approval to interview patients in Kenya, time and logistical constraints, the study was designed to interview the leaders of cancer patient support and advocacy groups, and obtain some of the cancer

patients' opinions. Excluding cancer patients in the study might have reduced the strength of some of the issues articulated by the patient support and advocacy groups. However, two of the seven leaders of these groups are cancer survivors and therefore able to partially offer a cancer patient's perspective.

Data on the cancer prevalence and incidence is largely estimated by WHO and the IARC, based on statistical models, and in the absence of a national cancer registry in Kenya to provide more reliable data. As such, the figures used in this study are the only ones publicly available, despite their apparent lack of verifiability.

6.3 Conclusion

Existing literature points out gaps that can be addressed to improve the timely access to cancer testing and treatment services in Kenya. Focusing on the three top adult cancers and the group of pediatric cancers can serve as a starting point for improving the diagnosis and treatment services in the country. However, this should not mean the diversion of attention or resources from other cancers that are curable with timely diagnosis and effective treatment. Effective treatment options can be developed to address cancer in a resource constrained environment where the technical expertise required to administer treatment modalities is yet to be developed. An in-depth look at effective cancer interventions and policies being implemented in countries facing similar challenges as Kenya can provide valuable lessons to Kenya's public and private sectors and policy makers.

Future studies can conduct in-depth patient interviews as part of measuring the impact of the ongoing policy implementation actions. Findings from such a study could contribute toward practice-based policy formulation, and potentially improve policy implementation in Kenya.

CHAPTER 7: POLICY IMPLEMENTATION RECOMMENDATIONS

This section presents recommendations based on the key informant responses and the policy analysis on actions that can be taken by the implementing organizations to improve access to cancer testing and treatment in Kenya. Additionally, responses from the majority of participants in this study indicated the need for an urgent implementation of existing cancer policies. As a result, this study applies findings from the semi-structured interviews and the policy literature review to recommend the implementation of the following: 1) health care financing through NHIF and non-discriminatory practices by private insurance firms, 2) Establishing county level cancer diagnosis and treatment facilities where none are existent but the need is high (decentralization), 3) Acquiring cancer diagnosis and treatment machines, and training health personnel to screen, diagnose and treat cancers and 4) increased public health awareness through dissemination of information about cancer.

7.1 Defining Policy Implementation

The National Implementation Research Network (NIRN) defines implementation as “a *specified set of activities designed to put into practice an activity or program of known dimensions*”⁶¹.

In this study, policy implementation is defined as a set of systematic activities conducted to achieve desired outcomes outlined within a policy’s goal. Policy implementation combines information and evidence collected through stakeholder consultations, literature and policy analysis in a contextualized environment. Applied

effectively, it can help build strong commitment to address the health and economic challenges faced at various levels of implementation.

Effective policy implementation requires a clear identification of goals, the roles and responsibilities of decision makers, and stakeholders.

7.2 Stakeholder Analysis

As part of reviewing Kenya's cancer policies, a stakeholder analysis identified key stakeholders and their roles in policy implementation. This list is in addition to the existing implementing entities' knowledge about fellow stakeholders in Kenya – namely the KNCI at the national level and the County Health Departments at the county level. Through this study, it further enables implementing entities to anticipate the influence of the most critical stakeholders, to address potential concerns and secure the support of key stakeholders at various implementation levels.

Through this analysis, the public sector, represented by KNCI and the county governments, is one of the entities with the highest level of influence in the implementation of cancer policies. In the current context, the government is positioned as the principle financier of public health activities. However, based on the government's annual health expenditure report, the private sector, through taxes and other levies, is the largest source of government funds. Diversifying funders could enable the government to secure the investments it needs to develop health facilities, purchase and install cancer diagnosis and treatment machines, and train health personnel to deliver cancer services.

The private sector through insurance companies and private health facilities yields significant power in adopting government policies that are designed to reduce barriers to cancer services. Based on the semi-structured key informant interviews, the private sector clinicians were skeptical of the impact of government policies on their delivery of cancer

services to patients. Greater involvement of the private sector clinicians could improve acceptance of government policies that affect access to cancer services in both private and public facilities.

In addition to private practice clinicians, insurance companies yield significant power and influence as financiers and stakeholders in Kenya's healthcare market. Any changes that mandate the coverage of high-cost interventions, such as cancer treatment, are most likely to result in resistance. Given the financial disincentive for insurance companies to pay for cancer testing and treatment services, changes will require an amendment to the current cancer Act (2012) through a vote of parliament or presidential order.

The patient support and advocacy groups are among the three most influential entities whose position and role can affect cancer policy implementation. To date, these groups provide cancer awareness and information to the public, in addition to conducting screening and diagnostic testing with the assistance of health facilities. Given the government's limited financial and technical capacity to reach target populations, it is worth recognizing the role of these groups. Planning interventions, while taking into account the support groups' positions, could help the government achieve some of its cancer policy goals, such as raising public awareness about cancer.

The media plays a central role in disseminating information about cancer to the public and policy makers. The media's focus on the state of cancer testing and treatment services in the country has increased the public's knowledge about the challenges faced by patients in the public hospital (KNH). This type of public awareness has equipped the cancer patient support and advocacy groups and put pressure on the government to address the challenges faced by patients seeking cancer testing and treatment in the country. The media's ability to

translate and transmit messages in the national languages (Swahili and English) and local dialects is a powerful tool that can serve the cancer policy implementers in Kenya.

The academic sector is represented by Kenyan universities and research bodies, such as AMREF and the Kenya Medical Research Institute (KEMRI). Research produced by these entities is typically in a scientific language, which requires interpretation for policy makers and implementers. As such, the role of academic partners in implementation of policies by KNCI and the county level governments appears limited at this point.

There is increasing interest by international groups, such as the American Cancer Society and the consortium of North American academic health centers (through AMPATH⁶), to support Kenya's cancer sector. Their involvement through financial and technical services is boosting access to cancer testing, treatment and palliative care for Kenya's cancer patients. Given the Kenyan government's lack of financial and technical capacity to implement cancer policies, reliance on these international entities could give them more power than currently apparent to the public to influence policy implementation. The table below summarizes the entities, their roles and level of influence.

⁶ "AMPATH is Moi University, Moi Teaching and Referral Hospital and a consortium of North American academic health centers led by Indiana University working in partnership with the Government of Kenya".- www.ampath.org

Table 6. Summary of Kenya's Cancer Sector Stakeholders, Their Roles and Levels of Influence

Stakeholder	Public	Private	Academic or Research	Media	Patient Support and Advocacy Groups	Others - International
Entity	GOK through the Ministry of Health, KNCI County level Cancer Prevention and Control groups	Private health providers and hospitals	Kenya Medical Research Institute (KEMRI) AMREF University Hospitals in Kenya	Local TV stations Kenyan newspapers Kenyan Public health journals	Examples include KENCO Women4Cancer Hope Beyond Cancer Childhood Cancer Initiative and others	World Health Organization/ International Agency on Research on Cancer (IARC) American Cancer Society AMPATH
Role	Creates policies, rules and regulations, enforces implementation, allocates resources to implement policies	Influence policy, rules and regulations, and cancer service delivery	Inform policy through research, implementation evaluation to promote evidence-based policies	Communicate to and on behalf of the public and policy makers, raise awareness about the availability of cancer diagnostic and treatment services	Inform policy through patient advocacy, facilitate access to information for cancer patients, raise public awareness about cancer, prevention and treatment options	Inform policy through financial and technical resources and research
Level of Influence on the implementation process	High GOK and MOH have the power to authorize, implement, finance or reject policies.	High Kenya's private health and public health services sector's power to influence implementation in the public and private health facilities.	Medium low Cancer research in Kenya seems to have a mild effect on the formulation and implementation of cancer policies.	Medium high As the main source of information for the public, the media can strongly influence the public's knowledge of cancer and health-seeking behavior	High Representing civil society, these groups engage with policy makers, provide compelling information on cancer to policy makers and the public, mobilize communities for cancer screening activities, can disseminate information on treatment locations	Medium Recent technical and financial support by the American Cancer Society and the consortium of universities through AMPATH at MTRH has led to increased screening and treatment for a subset of the patient population

7.3 Policy Implementation Goals

To apply findings from the semi-structured interviews and the policy literature review in addressing the four main issues cited by participants as critical to improving access to cancer testing and treatment in Kenya.

1. Financing cancer treatment.
 - a. To address cancer diagnostic and treatment costs. These include routine diagnostic tests such as mammograms for breast cancer and gene and biomarker tests once patients have a positive diagnostic. The costs of cancer drugs, cancer-related surgery and radiotherapy especially at private facilities.
 - b. To address the discriminatory practices of insurance companies.
2. The need to equip health facilities with equipment such as the radiotherapy machines, in addition to providing skilled personnel to operate the equipment, diagnose and treat cancer in the country.
3. The need to decentralize the delivery of cancer diagnostics and treatment services through the country's devolved governance and service delivery structure.
4. The need for government communication and information dissemination about cancer as an issue of significant public health concern.

These goals guide implementation activities, identification of indicators to measure progress, and the expected outcomes. These and other factors are presented in the implementation evaluation section using the logic framework.

7.4 Policy Implementation Stages

In this study, four implementation stages that lead to successful programs are recommended to improve the likelihood of successful implementation of the current policies governing access to cancer diagnosis and treatment in Kenya. The first three are compiled

from the NIRN's implementation stages guidelines. Additional policy implementation actions are identified from the ANOA's ⁶² better practice guidelines in policy implementation. The fourth step on program monitoring and evaluation is based on the logic framework, and the principal investigator's experience in implementation science. The image below (figure 7) depicts four proposed policy implementation stages based on this study's findings.

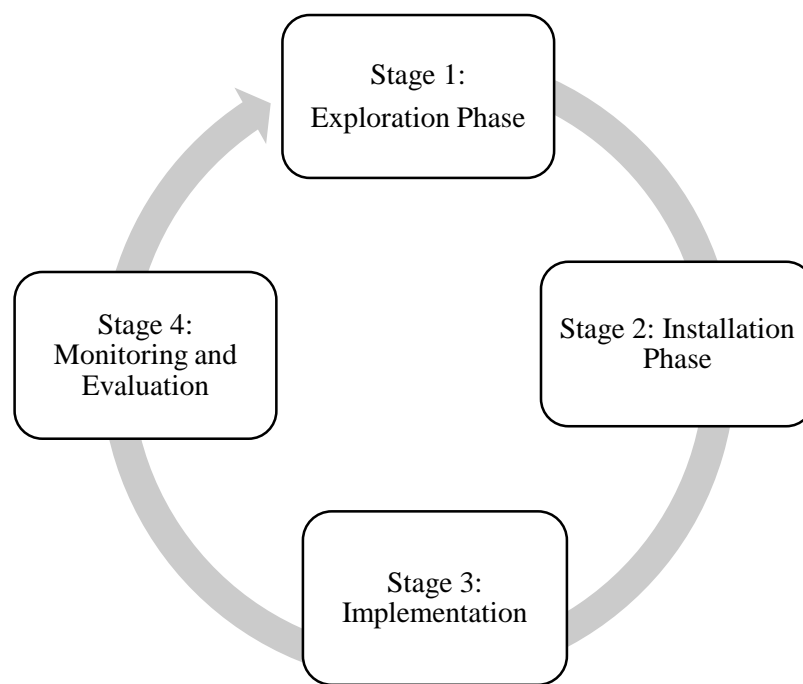


Figure 7. Recommended Policy Implementation Stages

7.4.1 Stage 1: Exploration Stage

For effective implementation, the national and county levels are required to identify a capable leader to lead the implementation process and team. Setting criteria for the desired qualifications and qualities of all leadership positions and the responsibilities of the role increases the likelihood of identifying the most suitable candidates ⁵⁹. The selection of KNCI's CEO and the appointment of County Health Directors positions these office bearers

as the leaders, unless otherwise noted by their offices, with the responsibility to lead cancer policy implementation at their respective levels. To increase stakeholder buy in, a transparent recruitment process can help address any perceived or real issues of corruption, nepotism and favoritism that could have a negative effect on the proposed interventions in Kenya.

During the exploration phase, the readiness of the counties to adopt activities that can improve access to cancer diagnostics and treatment can be assessed by an independent party for an objective opinion. The assessment could be conducted by a skilled implementation team that has experience in designing and implementing public health programs focused on improving access to health services for patients in Kenya. Knowledge of Kenya's cancer policy goals could enhance the implementation team's ability to identify the level of readiness in the targeted implementation locations.

A successful identification of the key preconditions and capabilities of the existing health systems at a county's level 5 hospital is critical for successful policy implementation. A checklist measuring indicators of readiness, such as the level of human resources, could be applied to enhance objectivity and provide decision makers and stakeholders with a fair assessment of the team's recommendation. An example of a checklist that can be applied at a county level is shown below (Table 8).

Table 7. Exploration Stage Activities Checklist

Resources	Yes or No
Human Resources	
Does the county have a board certified clinical oncologist?	
Does the county have a board certified pathologist?	
Does the county have board certified radiologists?	
Does the county have a board certified surgeon?	
Does the county have an oncology nurse?	
Facilities	
Does the county have a level 5 hospital (referral hospital)?	
Does the county have a clinical chemistry laboratory?	
Does the county have a hematology laboratory?	
Equipment	
Does the county have a radiotherapy treatment machine?	
Does the county have facilities to host radiotherapy machine?	
Other observations	

Data collected through the checklist by the implementation team should be shared with decision makers, in this case the county level health director and the county cancer prevention and control committees (established under the proposed Cancer Act Amendment (2015)). The next level of resource identification could be conducted through a capacity and needs assessment. This assessment would further explore the conditions and status of items identified through the checklist and the gaps that can be addressed through capacity building interventions, as well as the required amount of time, and type of resources.

7.4.2 Stage 2: Installation Phase

The objective of the installation phase is to acquire or repurpose the resources needed to carry out the work ⁶¹. The decision makers, including the county health director and the county cancer prevention and control committee members, would identify and select staff to serve in the implementation teams. Based on the roles of the implementation team members, they would assist in identifying space to serve as the office, selecting material and equipment such as computers, choosing the implementation location(s), creating goals and objectives of

the preparatory phase, establishing a timeframe, identifying progress indicators and establishing a monitoring mechanism for the interventions.

Timely and accurate communication during this installation phase is important in ensuring that the decision makers are well informed and able to make timely decisions that does not delay the preparation stage ⁵⁹.

Table 8. Installation Stage Activities Checklist

Activity	Yes or No
Have all stakeholders been identified?	
Have policy objectives been communicated to stakeholders?	
Have the policy objectives been communicated to staff?	
Has an implementation strategy been drafted and approved by decision makers?	
Has the implementation location been selected?	
Is there a communication plan for the beneficiary community?	
Have the type and amount of resources been identified?	
Have funds been secured?	
Other remarks	

7.4.3 Stage 3: Implementation Phase

Once the planning phase is completed, the implementation team with the support of the decision makers, can proceed to the initial implementation phase. During this phase, a pilot can be implemented in the county or selected counties if the implementation team is reviewing several potential counties. A pilot would enable the implementation team to obtain an early indication of the implementation plan's viability and take corrective action where needed. It also allows the team to confirm initial assumptions about the selected county's health system's capacity and identify the outcomes of any capacity building interventions delivered during the installation stage.

A policy communication strategy should also be implemented to increase the level of stakeholder and beneficiary commitment at the national and county levels, and reduce fears and concerns that could result in implementation delays. Using cancer policy communication guidelines provided by Kenya's MOH through the Cancer Prevention and Control Guidelines, the communication can be an effective tool for enhancing buy in and demonstrating early wins to the stakeholders. These guidelines take into account demographics of the audience: age, gender, level of education and cultural norms dictating how information is shared.

1. Through community meetings with elders, known locally as Chiefs' Barazas
2. Religious and cultural gatherings, including funerals
3. Public announcements during market days, using roadshows

Communication mediums can include:

1. Printed media in easily comprehensible languages
2. Use of images in printed mediums, such as billboards, murals, posters and T-shirts
3. Use of electronic messaging systems and platforms, such as text messages, Twitter, Facebook and online advertisements

An initial checklist for the initial implementation phase can include the following items:

Table 9. Implementation Stage Activities Checklist

Activity or Items	Yes or No
Have the initial implementation assumptions been identified?	
Have potential delays been identified and addressed with stakeholders?	
Have quality implementation standards been set and communicated to all stakeholders?	
Have issues that could affect implementation been identified?	
Are resources sufficient based on the pilot (trial)?	
Are progress indicators accurately identified to report program outcomes and impact based on each implementation phase?	
Has the monitoring and reporting system been tested?	
Have preliminary results been communicated to decision makers and stakeholders?	
Other observations	

Identifying issues that need correction before full implementation can result in a better allocation and use of resources at the national and county levels. Once a successful pilot has been demonstrated in one or a handful of selected counties, full implementation can follow. At this point, national and county level decision makers, stakeholders and beneficiaries should have a clear sense of the expected outcomes, benefits, challenges and timelines for the implementation of a cancer prevention and control programs in their communities.

7.5 Policy Implementation Framework

A policy implementation framework will allow Kenya's cancer sector decision makers and stakeholders to anticipate challenges, foresee risk and establish risk mitigation plans to address identified implementation obstacles. Identifying the sources of the obstacles can be used to establish dialogue with the concerned parties with the objective of seeking consensus or potential compromises ⁶³.

In the Real World Evaluation, Bamberger ⁶⁴ points out five sets of contextual factors that can help explain implementation and a program's results: economic, political, policy,

institutional and organizational. In this study, these factors are analyzed as risks that can adversely affect or positively influence the implementation of interventions to address barriers faced by cancer patients and clinicians delivering cancer services. These factors are presented in a logic framework to guide implementation.

A logic framework is defined as “a plausible and sensible model of how a program will work under certain environmental conditions to solve identified problems”

– Wholey et al., 2010⁶⁵

In this study, the logic framework is contextualized to respond to the policy implementation needs and to facilitate the identification of potential outcomes, risks and assumptions – all critical factors in the implementation location.

Table 10. Policy Implementation Logic Framework

Framework Concepts: Characteristics of the Health System Delivery and the Utilization of Health Services

Research Question: What are the patient characteristics, including level of cancer awareness, among people seeking access to cancer testing and treatment services, and which of these are modifiable through policy or other actions?

Policy Goal: Reduce barriers to diagnosis and treatment through interventions that improve the populations' access to accurate information and education about cancer and by reducing costs for cancer diagnosis and treatment

Inputs	Activities	Evidence of Indicators	Assumptions	Risks	Outcomes
<ul style="list-style-type: none"> •Accurate and contextually appropriate information about cancer signs, symptoms •Training clinicians on screening techniques • Baseline KAP survey 	<ul style="list-style-type: none"> •Public communication about availability of screening activities •Dissemination of information about cancer in written, audio and video formats through appropriate mediums •Measuring level of awareness in a sample of the population in the catchment area. 	<ul style="list-style-type: none"> •Clinical reports on number of people screened, results and referral records •Verbal and or written participants' witness of screening accounts •Results of follow-up KAP surveys 	<ul style="list-style-type: none"> •Timely dissemination of information •Skilled clinicians conduct screenings •Full disclosure of symptoms by patients •Availability of screening material and equipment 	<ul style="list-style-type: none"> •Patient misdiagnosis if clinician is not sufficiently skilled •High costs associated with screening low-risk patients •Increased anxiety and fear about cancer due to screening errors 	<ul style="list-style-type: none"> •Increased uptake of screening for the three most common cancers: prostate, cervical and breast cancer •Increased early (stage I or II) presentation by patients

Framework Concepts: Characteristics of the Population at Risk and Consumer Satisfaction

Research Question 2: How does the organization of health services and the health infrastructure affect access for patients?

Policy Goals: To decentralize cancer diagnostic and treatment, according to the 2015 proposed amendments to the 2012 cancer Act; improve ease of access to cancer diagnostic and treatment services and patient follow-up activities.

Inputs	Activities	Indicators	Assumptions	Risks	Outcomes
<ul style="list-style-type: none"> •Diagnostic equipment, e.g. mammogram machines for breast cancer •Treatment equipment, such as radiotherapy machine •Information and education material •Skilled cancer personnel •Cancer site-specific diagnostic and treatment 	<ul style="list-style-type: none"> •Equipment purchase and installation •Establishment of cancer diagnostic and treatment facilities at county level •Establishing clinicians' cancer diagnostic and treatment skills •Conducting customized cancer diagnosis and treatment skills trainings for clinicians 	<ul style="list-style-type: none"> •Records and proof of equipment acquisition •Pre-training and post-training clinicians' skill analysis reports •Functional cancer diagnostic and treatment services at county level •Patient records •Patient testimonies on type and quality of services delivered by trained clinicians 	<ul style="list-style-type: none"> •Availability of funds at county level to purchase and install equipment and pay for clinicians' training • Clinicians' willingness to be trained •Clinicians' are committed to undertake a complete training module •Availability of medical supplies and equipment during the implementation period •Cooperation of the county health and county cancer prevention and control committees •Availability of trainers 	<ul style="list-style-type: none"> •Lack of sufficient funds at the county level to simultaneously undertake the activities • Too much time lapses between personnel training and acquisition of equipment •Corruption leading to incomplete activities and fund misappropriation •Changes in senior leadership overseeing activities 	<ul style="list-style-type: none"> • Increased county level capacity to diagnose and treat cancer in a timely manner • A reduction in patients' anxiety associated with costs and logistics to access cancer services •Timely presentation of cancer cases •Timely treatment of cancer patients •A reduction in cancer mortality rates

Framework Concept: Health Policy Actions

Research question 3: What policy actions can improve access to timely cancer testing and treatment in Kenya?

Policy Goal(s): Implement current cancer policies and collect evidence to inform future amendments of the Cancer Act.					
Inputs	Activities	Indicators	Assumptions	Risks	Outcomes
<ul style="list-style-type: none"> •Allocation for cancer diagnosis and treatment funds by the NHIF and county level health budget •Revise clauses by private insurers •Funds to subsidize cancer treatment costs •Inclusion of cancer drugs in Kenya's essential medicine list 	<ul style="list-style-type: none"> •Revising the budget allocated to cancer from the current 6% to at least 15% •Clear positions by NHIF on coverage for all members •Change in insurance policies for cancer patients •Negotiation of favorable cancer drug prices with pharmaceuticals 	<ul style="list-style-type: none"> •Treasury and MOH records of increased allocations for cancer •Written public notification on revised NHIF policies in languages, locations and medium easily comprehensible by the public •Reduced cancer drug prices 	<ul style="list-style-type: none"> •The introduction and assent of a money bill if funding is from taxes, as stipulated in article 114 of the constitution •Subject to agreement by lawmakers on budget revisions in June 2016 (when the budget is approved in Kenya's parliament) •That private insurance firms are in favor of proposed inclusion of cancer patients 	<ul style="list-style-type: none"> •Lack of adequate controls at the fund holding entity could lead to funding misappropriation •Rejection of the proposed allocations by the decision makers and stakeholders 	<ul style="list-style-type: none"> •Favorable: increase in timely diagnosis •Increase uptake of treatments at the public and private facilities •Reduced cancer mortality rates •Reduced patients' out-of-pocket expenditures for cancer diagnostic and treatment services
<ul style="list-style-type: none"> •Technical support to counties implementing activities outlined in the cancer act. 	<ul style="list-style-type: none"> •Identification of county members to lead county level implementation •Identification of facilities to serve 	<ul style="list-style-type: none"> •County progress reports on the implementation of the aforementioned activities •Epidemiological data 	<ul style="list-style-type: none"> •Commitment of political, local and any non-local stakeholder •Cooperation of all decision makers 	<ul style="list-style-type: none"> •Competing county agendas •Waste of resources, if cancer burden is low 	<ul style="list-style-type: none"> •Easier access to cancer diagnosis and treatment services at the county level •Evidence to support future

	as county cancer hospitals •Establishment of the county's clinicians' skill levels and training needs •Research on the prevalence and incidence rates of cancer in each county •Establishment of county level policy on cancer information management to the public, KNCI and other stakeholders	•Physical evidence of equipment, machines, medical supplies and cancer treatment drugs	and service providers •Proper management of funds and any non-monetary resources •Adherence to a timeline	•Increased patient load if neighboring county has high cancer burden and no facilities	cancer act amendments
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The above listed activities are not exhaustive due to the complex nature of implementing new policies. This logic framework enables the implementing organizations to modify the activities, assign responsibilities and establish the most appropriate timeframe to complete the activities. It also recognizes that some of the policy actions, such as the establishment of the KNCI, have been completed.

7.5.1 Stage 4: Policy Implementation Monitoring and Evaluation

As mentioned above, implementation of some of the cancer prevention and control activities is currently in process in selected counties. However, without a policy implementation evaluation, the extent of progress achieved through these policies is unclear to most stakeholders and the public, as indicated by participants in this study's semi-structure key informant interviews.

The indicators and outcomes listed in the logic framework can enable the principle actors to identify steps required to deliver activities, measure progress and evaluate the effectiveness of the interventions. It also enables evaluators and stakeholders at the national and county level to link the indicators to an activity and determine the extent to which it has been completed, as well as its effect on the related policy goal.

Actions to evaluate progress of the above interventions can be guided by four main principles of effective evaluation listed by Wholey et al ⁶⁵ in the handbook of practical program evaluation. These four principles are utility, feasibility, propriety and accuracy. Determining the usefulness of an evaluation (utility), the costs, time and resources (feasibility), the application of sound data collection methods, analysis and reporting (propriety), and the reliability of the data and the data collection tools (accuracy) are important considerations for evaluating the extent of cancer policies and guideline implementation.

The first step in the application of these four principles is to determine the principle users of the evaluation results and how the information would be used. Based on literature about the organization of cancer prevention and control in Kenya, the KNCI as the coordinating body on all matters related to the prevention and control of cancer in Kenya, together with the county cancer prevention and control committees, would be the primary consumers of information collected from an implementation evaluation. The interest levels of other entities identified through the stakeholder analysis could be subjective.

In order to review progress of implementing activities that reduce access barriers for cancer patients, an evaluation assessment⁶⁶ is recommended for its low-cost approach. Cost is an important consideration in a financially constrained environment like Kenya where additional financial commitments to evaluate implementation of policy actions could be hard to secure if it is deemed costly by decision makers.

Based on the advantages of using evaluation assessments shared by Leviton et al. in the article on public health policies and programs ⁶⁶, we recommend the use of an evaluation assessment in the monitoring and evaluation phase. Its suitability to this study is based on the fact that cancer policy implementation in Kenya's is in its early stages and can be strengthened through evidence-based practices.

In this case, an evaluation assessment will enable evaluators of the activities to improve access to cancer services at the county and national level to : a) provide quick and constructive feedback to the implementing entities, b) encourage timely corrective actions, c) be tailored to meet national and county regulations for reporting on public expenditures d) further translate studies such as this one into practice by examining the feasibility of the proposed interventions in new locations (county level) as part of the decentralization of

cancer services; and e) translate practice into research by using lessons learned from the implementation of policies into counties to meet the country's research needs.

Findings of the evaluation assessment can be used to inform ongoing cancer policy interventions and future cancer prevention and control programs in Kenya.

CHAPTER 8: PLAN FOR CHANGE

Decentralized cancer testing and treatment centers in Kenya addresses one of the findings of this study – that is the need to eliminate long patient wait times at the only public hospital that offers comprehensive cancer treatment.

Six counties – Nairobi, Kiambu, Machakos, Kisumu, Eldoret and Mombasa – are working toward the establishment of cancer diagnosis and treatment centers. This leaves out 41 counties still in need of cancer treatment facilities.

The following implementation actions are proposed to the counties and KNCI, based on their role in the proposed 2015 amendments of the 2012 cancer Act. However, recognizing the complexity of implementation, the scarcity of resources and the urgency to improve access to cancer testing and treatment services, the actions are presented in two categories: 1) Short term- these can be implemented over the next 1-3 years, resources could be available and results demonstrated within 12-24 months; 2) Long-term- these can be implemented over the next 3- 5 years or more, require significant resources and stakeholder support. Though results can be demonstrated over a 12-24 month period, due to the complex relationships and processes required to implement them, they are considered as long-term activities.

8.1 Short-term Implementation Actions

1. Address Cancer Diagnosis and Treatment Costs: These remain the leading barrier facing people seeking cancer services in Kenya. Clinicians delivering cancer services in Kenya are aware that their services are out-of-reach for the majority of self-paying and

underinsured patients. And among insured patients, discriminatory practices by insurance companies – such as capping coverage and increasing premiums – lead to significant anxiety. The public insurance through NHIF has begun paying for cancer diagnosis and treatment. However, two main gaps were identified with the current NHIF policy: First, coverage criteria is unclear to the public and clinicians and second, the majority of the study participants were unaware that NHIF was paying for cancer treatment within the country. The latter stems from recent public communication by NHIF that it would pay for up to KSH 5 million (US\$ 50,000) for cancer treatment outside of the country. Among the clinicians interviewed, this approach appears ill-informed due to the additional costs such as airfare and accommodations that patients and most likely a caregiver have to incur while abroad. Based on findings, NHIF needs to revise its policy, communicate coverage criteria to the public and provide coverage to all paying members – not only a selected group. In cases where financial barriers are likely to result in patients not seeking or completing cancer treatment, viable financial support systems through the NHIF or other viable mechanisms or charities could be beneficial to patients (Mostert et al., 2014). At this point, the government's best option is to use NHIF to finance patient diagnostic and treatment costs for patients inside the country or outside, if deemed appropriate.

2. Create a National Cancer Education and Awareness Program: The government needs to create and implement a public health education program on cancer that targets the general public. Accurate information leads to better awareness about cancer and can help counter the myths and misinformation surrounding the disease. Community consultation and participation in designing culturally and language appropriate educational materials will result in changes in the population's health-seeking behavior, and potentially

result in an increase in the timely uptake of cancer testing services and lower cancer mortality rates. Assessments to determine the population's level of knowledge, awareness, attitudes and beliefs, are critical in shaping public health messages needed to reduce some of the barriers cited earlier in this study.

3. Improve Patient Provider Communication: In Kenya, where provider opinion is revered, there is a need for better communication by the doctors and nurses to patients. For parents of children diagnosed with cancer, this communication is important in enabling the parents to cope with the stress and anxiety associated with their child's disease. It can reduce treatment interruptions and help ensure a higher treatment completion rate (Njuguna et al., 2014). Hospital policies on patient imprisonment due to unpaid medical bills needs to be abolished as they negatively impact the patient-provider relationship, and erode the potential benefits of provider involvement in ensuring treatment adherence and completion (Mostert et al., 2014).

4. Use Primary Healthcare Facilities as Entry Points for Cancer Services: In Kenya, like many other countries, primary healthcare facilities serve as the entry point for patients presenting with various symptoms. As such, providers at these facilities in Kenya should be trained and equipped to screen high-risk patients, such as those with a known family history of cancer, with predisposing factors such as HIV/AIDS or patients based on international screening guidelines that have also been adapted by Kenya's MOH through the Cancer Prevention and Management Guidelines³⁵. Inexpensive screening techniques for the three most prevalent cancers in Kenya, cervical, breast and prostate, can be applied by skilled health personnel and increase the timely diagnosis of more than 50% of the cases presenting as advanced. These techniques could use visual inspection with acetic acid or Lugol's Iodine

for cervical cancer, breast self-examination (BSE) and clinical breast exams (CBE) for breast cancer screening, and digital rectal exams (DRE) or prostate specific antigen (PSA) test for prostate cancer. Available at the primary care, county and national level hospitals, these tests can be performed by trained doctors, nurses and other clinical officers serving in these facilities.

8.2 Long-term Implementation Actions

5. Strengthen the Capacity of Existing Health Facilities: In 2015, the Kenya government and international stakeholders agreed to strengthen the capacity of KNH and MTRH and, establish cancer centers in Kiambu, Mombasa and Kisumu counties as part of a phased approach to availing access to cancer services at the county levels. In light of efforts by other counties, such as Machakos, the government needs to let the public know the criteria used in determining the prioritization of establishing county level cancer centers. Criterion could enable the public and other stakeholders to gain a better understanding of the determining factors and engage with the government and counties accordingly.

Unfortunately, diagnostic equipment and skilled personnel are concentrated at the national level. However, the ongoing decentralization process will further enable an additional number of county level hospitals to upskill their clinicians and install equipment needed to diagnose cancers.

6. Invest in Training Health Personnel and Equipping Health Facilities: In addition to personnel training, investments into health infrastructure and medical supplies for cancer testing could reduce the time lapse between diagnosis and treatment and result in better health outcomes for patients. The installation of equipment such as CT scanners, ultrasound, mammography and magnetic resonance imaging (MRI) equipment at county level health facilities could reduce the time lost through patient referrals. Alternatively,

mobile MRI facilities could be shared by counties and reduce the high patient backlog at the national hospital, while also enabling timelier diagnosis and the onset of treatment that could improve cancer survivor rates in the country. The feasibility of a mobile MRI unit would be subject to evaluations that are currently beyond this study's scope.

8.3 Next Steps

This study was originally designed to propose amendments to the cancer Act 2012, however most of the initially targeted amendments were addressed through section IIA⁷ of the amended cancer Act 2015. Despite these changes, the need to reduce the cost of cancer screening and treatment services is recognized as a major issue by clinicians and patient support group leaders. Quantifying the cost of screening and diagnostic services, as well as the costs of various cancer treatment drugs, related surgeries and radiotherapy will enable us to further advocate for amendments that include coverage of cancer testing and treatment in the current cancer Act. Pending further discussions with policy makers, I will take the following actions to support this study's findings.

1. Share this study's findings. I will disseminate this study's findings among Kenya's cancer policy makers, which include elected officials, the government through the Ministry of Health's department of Non-Communicable Diseases, the Kenya National Cancer Institute and among member organizations of the Kenya Network of Cancer Organizations. A copy of the study will be made available to study participants via email. I also plan on making a presentation at the newly instituted quarterly cancer stakeholders meetings in Nairobi by the end of 2016. Through personal contacts, I will be sharing a copy of the study with a group of American Cancer Society researchers designing various patient

⁷Section IIA—County Cancer Prevention and Control Committees.

access portals through Kenya's national hospital, Kenyatta National Hospital. And lastly, I will also share a copy of the study with University of North Carolina's Lineberger Cancer Center's Patient-Centered Outcome Research group due to its support in the form of a travel grant to collect data for this study.

2. Engage policy makers: In addition to sharing findings with policy makers, I am pursuing discussions with Kenya's lawmakers (parliamentarians) in the health committee and have established contact. The next step is to create a policy brief with a summary of findings and proposed policy implementation actions.

3. Support Resource Mobilization" Based on my experience in the philanthropic sector, I anticipate supporting the implementing organizations in seeking funding to implement some of the interventions through civil society. Where feasible, I plan on supporting the government at the national and or county levels to mobilize financial and technical resources that facilitate priorities listed in the current national cancer policies.

4. Publishing: To make the study widely available and inform future research, the study will be published in relevant journals.

APPENDIX 1: LIST OF CANCER TESTING AND TREATMENT FACILITIES IN KENYA

Name of facility	Location	Type of facility	Type of services
Aga Khan University hospital	Nairobi	Private	Screening, specialized diagnostics, chemotherapy and radiotherapy treatment, palliative and rehabilitation
Beacon Health Services Cancer treatment center	Nairobi	Private	Diagnosis and out-patient treatment services
Coast Province General Hospital	Mombasa	Public	Screening, chemotherapy and surgery
Kenyatta National Hospital	Nairobi	Public	Screening, chemotherapy, surgery, radiotherapy and palliative care
Kijabe Mission Hospital	Kijabe	Mission	Screening, chemotherapy and surgery and palliative care
Mater Hospital	Nairobi	Private	Testing services, surgery and general cancer management services
Moi Teaching and Referral Hospital	Eldoret	Public	Education, screening, diagnosis, treatment and palliative care
M.P. Shah Hospital/Cancer Care Kenya	Nairobi	Private	Diagnosis, chemotherapy and radiotherapy
Nairobi Hospital	Nairobi	Private	Screening and chemotherapy
Nairobi Women's Hospital	Nairobi	Private	Testing and treatment
Texas Cancer Centre	Nairobi	Private	Diagnosis, systemic therapy/chemotherapy and surgery
Tenwek Mission Hospital	Bomet	Mission	Screening, treatment, stenting and palliative care services

APPENDIX 2: LITERATURE REVIEW RESULTS TRACKING TABLE

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Abdallah,F.K.; Macharia,W.M. 2001	Clinical presentation and treatment outcome in children with nephroblastoma in Kenya	East African Medical Journal	Childhood Cancer (nephroblastoma)	Retrospective analysis	803	Late presentation, advanced disease - 85% in stage III, IV and V; poor availability of cytotoxic drugs; frequent treatment interruptions
Agurto, I., Arrossi, S., White, S., Coffey, P., Dzuba, I., Bingham, A., et al. 2005	Involving the community in cervical cancer prevention programs.	International Journal of Gynaecology and Obstetrics: The Official Organ of the International Federation of Gynaecology and Obstetrics	Cervical Cancer	Article- Lessons Learnt	35	Barriers to cervical cancer screenings in low-resource settings include poor availability of services, poor quality of care, a lack of information, cultural and behavioral practices, and fear of death. Enhancing appropriateness of services by creating culturally sensitive education material and interventions could lead to increased demand for services, higher rates of treatment completion and lower disease burden. Working through community structures such as women's groups can enable outreach services to reach these women who would not otherwise seek services in conventional health facilities. Devising communication strategies to reach low literacy women can be a challenge however it could also be effective.

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Caleb, G. G. O. 2006	Breast carcinoma at coast province general hospital-mombasa kenya.	East and Central African Journal of Surgery	Breast	Retrospective	43	Late presentation, a need for awareness and early screening could improve outcomes for cancer patients. Predisposing factors such as a family history of cancer, early menarche and late menopause, spinsters, late age at first pregnancy, existing ovarian or endometrial cancer unilateral breast cancer. The use of improved treatment therapies and early diagnosis could result in better outcomes for breast cancer patients.
Duron, V., Bii J., Mutai, R., Ngetich, J., Harrington, D., Parker, R., et al. 2013	Esophageal cancer awareness in bomet district, kenya.	African Health Sciences	Esophageal	KAP Survey	81	Costs to obtain medical tests and fear cancer were cited as the leading reasons for delayed presentation by patients. Transportation costs to health facilities were also cited.
Gatune, J.W.; Ny amongo, I.K. 2005	An ethnographic study of cervical cancer among women in rural Kenya: is there a folk causal model?	?	Cervical Cancer	KAP study	191	lack of accurate knowledge, myths and cultural practices that hinder discussions on cervical cancer were present; fear of incurability was reported

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Gichangi,P.; Estambale,B.; Bwayo ,J.; Rogo,K.; Ojwang,S.; Opiyo, A.; Temmerman, M. 2003	Knowledge and practice about cervical cancer and Pap smear testing among patients at Kenyatta National Hospital, Nairobi, Kenya	International Journal of Gynaecologic Cancer	Cervical Cancer	KAP study	1353	Increased awareness could result in uptake of facility based cervical cancer screening; incorrect knowledge about cervical cancer risk; sources of information varied with friends and relatives cited as the most frequent source of information followed by clinicians-nurses and doctors. There is a significant unmet need for appropriately packaged cervical cancer information for users. Poor usage of Pap smear testing for cervical cancer screening. Need to strengthen health facilities to perform Pap smears.

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Huchko, M. J., Bukusi, E. A., & Cohen, C. R. 2011	Building capacity for cervical cancer screening in outpatient HIV clinics in the nyanza province of western Kenya.	International Journal of Gynaecology and Obstetrics: The Official Organ of the International Federation of Gynaecology and Obstetrics	Cervical Cancer	Retrospective	3642	Use of visual inspection with acetic acid (VIA), colposcopy, and loop electrosurgical excisions procedure (LEEP) were added to a family HIV care and treatment facility in Kisumu, Kenya. Results indicated that screening for cervical cancer within HIV care and treatment facilities is feasible, acceptable and effective. In this study, reasons for declining screening included “needing to talk with their husband,” “being on their menses,” “needing to think about it,” and expressing fear of the speculum exam. 28 clinical officers representing 90% of the clinical staff at the health facility were trained in VIA and colposcopy during the first three years of the program. These staff reported a high level of satisfaction with the training and application of new skills. However, the main challenges reported were related to infrastructure limitations (lack of water, electricity and supplies; and long waits in the clinic) and perceived patient barriers. A screening algorithm was applied. Samples were sent to Nairobi for testing and results conveyed by email. Clients in need of radiation were sent to Nairobi and surgical cases referred to the Kisumu provincial hospital.
Huchko, M.J.; Sneden, J.; Sawaya, G.; Smith-McCune, K.; Maloba, M.; Abdulrahim, N.; Bukusi, E.A.; Cohen, C.R. 2014	Accuracy of visual inspection with acetic acid to detect cervical cancer precursors among HIV-	International Journal of Cancer	Cervical Cancer	Cross-sectional	1432	VIA is an effective low-cost method to screen for cervical cancer. It reduces incidence and mortality rates

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
	infected women in Kenya					
Joelle I Rosser, Jennifer M Zakaras, Sabina Hamisi, and Megan J Huchko 2014	Men's knowledge and attitudes about cervical cancer screening in Kenya	BMC Women's Health	Cervical Cancer	Oral Survey	110	As access to cervical cancer screening programs improves in resource-poor settings, particularly through the integration of HIV and cervical cancer services, it is important to understand the role of the male partner's support in women's utilization of screening and treatment.
Kamau,R.K.; Oso, A.O.; Njuguna, E.M. 2007	Effect of diagnosis and treatment of inoperable cervical cancer on quality of life among women receiving radiotherapy at Kenyatta National Hospital	East African Medical Journal	Cervical Cancer	Cross-sectional descriptive		Effect of inoperable and advanced cervical carcinoma affects patients quality of life; marital discordance, reduced social engagements; lower financial health

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Kiarie G.W., Abinya N.O., Joshi M.D, Lule G.N., & Mutuma G.Z. 2010	Familial Clustering of Cancer in Two Tertiary Care Hospitals in Nairobi, Kenya	East African Medical Journal	45 different cancers- most common breast and uterine-cervical malignancies	Cross-sectional descriptive study	485	Prevalence of familial history of cancer reported in 18.8% of interviewees with first degree relatives exhibiting highest rates. Breast cancer familial history was reported at 36%, while the other cancers had lower or no familial cancer prevalence rates. These findings indicate a need for targeted testing for at-risk groups – those families with a known history of cancer. The results would be a timely diagnosis with improved patient outcomes.
Kisuya,J.; Wachira,J.; Busakhala,N.; Naanyu,V.; Chite,A.F.; Omenge,O.; Otieno,G.; Keter,A.; Mwangi,A.; Inui,T. 2015	Impact of an educational intervention on breast cancer knowledge in western Kenya		Breast Cancer	KAP survey	532	Breast cancer education and awareness can increase timely diagnosis and treatment and reduce the prevalence on late presentation
Kitonyi, G. W., Macharia, W. M., Mwanda, O. W., & Pamnani, R. 2009	Clinico-pathologic characteristics and treatment outcomes in children with neuroblastoma at the Kenyatta national	East African Medical Journal	Cervical Cancer	Cross-sectional descriptive study	26	Late presentation at stage IV of the disease. 19.2% survival rate one year after treatment and 7.7% survival rate two years after treatment. Only 1 of the 26 patients was still alive and disease free five years after diagnosis. Pathologic evaluation was absent partially due to the unavailability of services. Poor record keeping at health facility was cited as contributing to poor treatment interventions.

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
	hospital, Nairobi					
Kivuti-Bitok, L. W., McDonnell, G., Pokhariyal, G. P., & Roudsari, A. V. 2012	Self-reported use of internet by cervical cancer clients in two national referral hospitals in Kenya.	BMC Research Notes	Cervical Cancer	Cross-sectional	199	This study was conducted in two main hospitals: Kenyatta National Hospital- KNH and Moi Referral & Teaching Hospital (MRTH), which receives 70% of the nation's cervical cancer cases. Interviews conducted on patients using an open ended questionnaire, indicated high reliance on TV and radio for information on cervical cancer. The internet was used by only 7.1% of the respondents to obtain information on cervical cancer. The study demonstrates a limited use of internet in low resource settings such as Kenya as a source of information on cervical cancer. Users reported a higher level of education and income when compared to non-users. As such, education and awareness should be conducted through the most commonly used outlets, TV and radio.
Kivuti-Bitok, L. W., Pokhariyal, G. P., Abdul, R., & McDonnell, G. 2013	An exploration of opportunities and challenges facing cervical cancer managers in Kenya.	BMC Research Notes	Cervical Cancer	Cross-sectional descriptive study	33	The four themes that emerged were patient-related challenges: late presentation, limited knowledge about cervical cancer, poor attitudes by health workers, patients and relatives, personal and cultural levels of discomfort with the invasive screening procedure; individual health care provider challenges - large workload and high patient volumes, uncomfortable performing invasive screening procedures, lack of skills to handle complex cases of cancer; health facility related challenges- one publicly available radiotherapy in entire country, lack of electronic/ computerized systems.

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Magoha, G.A.O 2000	Management and survival in advanced prostate cancer in Nairobi	East African Medical Journal	Prostate Cancer	Prospective case study	59	Late presentation, poor outcomes with high morbidity rates
Maranga, I. O., Hampson, L., Oliver, A. W., Gamal, A., Gichangi, P., Opiyo, A., et al. 2013	Analysis of factors contributing to the low survival of cervical cancer patients undergoing radiotherapy in Kenya.	PloS One	Cervical Cancer	Prospective cohort study	355	80.5% patients presented with late stage or advanced stage IIB disease resulting in higher mortality to incidence ratios. Lack of education and awareness led to low levels of diagnosis and treatments. Simple cost-effective changes in clinical practice could result in improved patient survival rates.
McFarlane, G., Forman, D., Sitas, F., & Lachlan, G. 2001	A minimum estimate for the incidence of gastric cancer in eastern Kenya.	British Journal of Cancer	Gastric	Retrospective	200	This study used hospital records and statistical models to estimate the number of gastric cancer cases in Kenya's Eastern provinces. Figures were compared to neighboring country of Ethiopia and Eastern Europe. A gastroscopy service was installed in the province's referral hospital to screen for gastric cancers.

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Mostert, S., Njuguna, F., Ven, P. M., Olbara, G., Kemps, L. J. P. A., Musimbi, J., et al. 2014	Influence of health-insurance access and hospital retention policies on childhood cancer treatment in Kenya.	Pediatric Blood & Cancer	Childhood Cancers	Retrospective + Case study	222	Kenyan hospitals detain patients until they pay their medical bills. In this study, patients insured through Kenya's National Health Insurance (NHIF) were less likely to abandon treatment when compared to those without insurance. 32% of NHIF insured patients had an event free survival rate two years after completing treatment when compared to 16% for patients without NHIF or any other insurance. The patient retention policy has negative impact on patients and contributes to patients discontinuing treatment and premature deaths. Kenya's health policy needs to change to allow patients to seek cancer testing and treatment without the fear of being "imprisoned" at the hospital as a result of accrued medical costs.
Mostert,S.; Njuguna,F.; Olbara,G. ; Sindano,S.; Sita resmi,M.N.; Supriyadi,E.; Kaspers,G. 2015	Corruption in health-care systems and its effect on cancer care in Africa	Lancet Oncology	NA	Position Paper		Effect of corruption on patient's access to treatment, drugs and qualified personnel. Impact on patient's ability to seek and or adhere to treatment

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Mungo, C., Cohen, C. R., Maloba, M., Bukusi, E. A., & Huchko, M. J. 2013	Prevalence, characteristics, and outcomes of HIV-positive women diagnosed with invasive cancer of the cervix in Kenya	International Journal of Gynaecology and Obstetrics: The Official Organ of the International Federation of Gynaecology and Obstetrics	Cervical Cancer	Retrospective study	4308	Cervical cancer screening for HIV positive women in Kisumu, Western Kenya resulted in early detection. However, despite treatment, recurrence among this group of patients was high. Increasing access to screening in low resource settings within the country can probably shift the pattern of disease stage at diagnosis, resulting in more treatable early stage disease treatment. Long wait times, high co-payments and lack of health personnel at the health facility all contribute to lack of treatment access.
Mutebi, M., Wasike, R., Mushtaq, A., Kahie, A., & Ntoburi, S. 2013	The effectiveness of an abbreviated training program for health workers in breast cancer awareness: Innovative strategies for resource constrained environments	Springerplus	Breast	Communication	79	Health workers can play a critical role in raising awareness about breast cancer in Kenya where pre-menopausal women (35-45 yrs. and 10-15 yrs. earlier than Caucasian women) present with the disease. In-service training of nurses, at the Agah Khan University Hospital in Nairobi, enhances their knowledge and skills enabling them to screen patients at risk of cancer and detect breast cancer. With these skills nurses can raise awareness among patients and general population, resulting in a timelier cancer detection.

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Muthoni,A.; Miller,A.N. 2010	An exploration of rural and urban Kenyan women's knowledge and attitudes regarding breast cancer and breast cancer early detection measures	Health Care for Women International	Breast Cancer	KAP study	Eight Focus Groups	Lack of knowledge, financial barriers or costs, cultural beliefs (witchcraft) and the need for access to accurate information.
Ngugi, C., Wangari, Boga, H., T., Wanzala, P., & Mbithi, J., N. 2012	Factors affecting uptake of cervical cancer early detection measures among women in Thika, Kenya.	Health Care for Women International	Cervical Cancer	KAP survey	50	Lack of cancer awareness, fear of the potential negative results from screening, lack of emotional support from spouses, security concerns by spouses if one has to travel long distances especially overnight to a health facility for screening which is the case in rural areas, were indicated as deterrents to seeking cervical cancer testing.

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Njuguna,F.; Mostert,S.; Seijffert, A.; Musimbi,J.; Langat,S.; van der Burgt,R.H.; Skiles,J.; Sitaresmi,M.N.; van de Ven,P.M.; Kaspe rs,G.J. 2015	Parental experiences of childhood cancer treatment in Kenya	Supportive Care in Cancer	Childhood Cancers	Cross-sectional	115	The need for parental support- information and finances when children have cancer; the fear of parents to ask for more information from doctors; the need for doctors to improve communication to parents of children being treated for cancer. Cancer programs should include more support for parents: financial assistance, a facility where parents and children can stay during the course of therapy, and parent support groups.
Njuguna,F.; Mostert,S.; Slot,A.; Langat,S.; Skiles,J.; Sitaresmi,M.N.; van de Ven,P.M.; Musimbi,J.; Muliro,H.; Vreeman,R.C.; Kaspe rs,G.J. 2014	Abandonment of childhood cancer treatment in Western Kenya	Supportive Care in Cancer	Childhood Cancers	Cross-sectional	222	Treatment abandonment-Prevention of childhood cancer treatment abandonment requires improved access to health insurance, financial or transportation support, proper parental education, psychosocial guidance and ameliorated communication skills of healthcare providers.
O'Brien,M.; Mwangi-Powell,F.; Adewole,I.F.; Soyannwo,O.; Amandu a,J.; Ogaja,E.; Okpeseyi,M.; Ali, Z.;Kiwanuka,R.; Merriman,A. 2013	Improving access to analgesic drugs for patients with cancer in sub-Saharan Africa	Lancet Oncology	Access to Pain drugs	Paper on Cancer Control in Africa	NA	Late presentation, increased cancer burden and the need for pain management drugs and training for health personnel

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Onyango F.M, & Macharia, I.M 2009	Delays in diagnosis, referral and management of head and neck cancers presenting at Kenyatta National Hospital, Nairobi	East African Medical Journal	Head and neck	Prospective descriptive study	44	Patients went through multiple referrals to get to KNH taking anywhere from 0 to 8 months. Late presentation, low literacy levels, lack of knowledge about cancer were cited- only 34% of the patients knew or were informed by their providers about cancer. 45% of the cases presented to a health facility within one month of noticing symptoms and 45% after three months. Tumor stages varied by the time of presentation at KNH from 2% in stage I to 56% in stage IV with stages II and III having 6% and 14% respectively. Patient delay in seeking care can be attributed to the referral system in Kenya. Provider delay in making a diagnosis and instituting treatment add to the lag time between disease onset and treatment and significantly impact on survival. Only 16% of the sample population had received appropriate treatment by the time they arrived at KNH, indicating a lack of skill and capacity at different levels of the health personnel in the referral system in Kenya.
Otieno,E.S.; Micheni,J.N.; Kimende,S.K.; Mutai,K.K. 2010	Delayed presentation of breast cancer patients	East African Medical Journal	Breast	Prospective Cross-sectional	166	Late presentation at least more than three months after the onset of symptoms. Reasons include fear of being told about cancer, lack of pain, misdiagnosis by provider

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Rosser,J.I.; Njoroge,B.; Huchko, M.J. 2015	Cervical Cancer Stigma in Rural Kenya: What Does HIV Have to Do with It?	Journal of cancer education : the official journal of the American Association for Cancer Education	Cervical Cancer	Cross-sectional	419	Reducing cervical cancer stigma in the general population is an important part of promoting screening in sub-Saharan Africa.
Sayed, S., Moloo, Z., Bird, P., Wasike, R., Njoroge, W., Karanu, J., et al. 2013	Breast cancer diagnosis in a resource poor environment through a collaborative multidisciplinary approach: The Kenyan experience.	Journal of Clinical Pathology	Breast	Article- Lessons Learnt	NA	Advanced testing of breast cancer patients to determine best line of treatment depending on HER neu status is not widely available in Kenya, and its lack diminishes the chances of targeted therapies that could improve outcomes and quality of life for survivors. Where available, in Nairobi Hospital, high costs pose a barrier to patients who could potentially benefit from targeted therapy.
Strother, R. M., Rao, K. V., Gregory, K. M., Jakait, B., Busakhala, N., Schellhase, E., et al. 2012	The oncology pharmacy in cancer care delivery in a resource-constrained setting in western Kenya.	Journal of Oncology Pharmacy Practice : Official Publication of the International Society of Oncology Pharmacy Practitioners	NA	Articles/ lessons learnt	x	Cost of care is a major obstacle to delivering cancer care.

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Strother,R.M.; Fitch,M.; Kamau,P.; Beattie,K.; Boudreau,A.; Busak halla,N.; Loehrer ,P.J. 2012	Building cancer nursing skills in a resource-constrained government hospital	Supportive Care in Cancer	Nurse training	Communication		Recommendations on health-workforce (nurses) upskilling in Western Kenya
Sudenga, S. L., Rositch, A. F., Otieno, W. A., & Smith, J. S. 2013	Knowledge, attitudes, practices, and perceived risk of cervical cancer among Kenyan women: Brief report.	International Journal of Gynecological Cancer : Official Journal of the International Gynecological Cancer Society	Cervical Cancer	Cross-sectional	388	Fear, long wait times to see a doctor, lack of knowledge about the disease contribute to late presentation. Older women >37 years of age, are more likely to seek testing than younger ones. Level of education, income and awareness increase likelihood to get screening and treatment. Recommendations by medical personnel, symptoms such as uncontrolled bleeding and pain also increase likelihood of screening.
Wanyoike P.K 2004	Posterior cranial fossa tumours in children at Kenyatta National Hospital, Nairobi	?	Childhood Cancer (posterior cranial fossa tumours)	Retrospective analysis	37	Late presentation at least 3.7 months post symptoms

Author(s) and Year	Title	Journal	Type of Cancer	Method(s)/ Type of Study	Sample size	Findings
Were, E., Nyaberi, Z., & Buziba. 2011	Perceptions of risk and barriers to cervical cancer screening at Moi teaching and referral hospital (MTRH), Eldoret, Kenya.	N. African Health Sciences	Cervical Cancer	Cross-sectional	219	Older women > 30 years of age were more likely to have been screened than younger ones. Fear and financial costs were cited as barriers to accessing screening or treatment services. Awareness and educational messages should clarify the meanings and consequences of possible test results to patients to alleviate barriers such as those cited here in.

APPENDIX 3: STUDY INFORMATION AND CONSENT FORM

Informed Consent Form

Study Title	How Can Access To Cancer Diagnosis and Treatment Services Be Improved In Kenya?
Investigator(s)	Louise Kathini Makau-Barasa (Doctoral Student)
Study Sponsor(s)	Not Applicable
Collaborators	Student's Advisor- Dr. Antonia Bennett

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Hello, my name is Louise Makau-Barasa, a doctoral student at the University of North Carolina at Chapel Hill, North Carolina USA. You have been chosen at random to be in a research study about improving access to cancer testing and treatment services in Kenya.

We are giving you this information because we would like you to participate in our research project. We want to make sure that you have all the information that you need before you decide. If you do not understand any of the words or ideas that you see on this form, please ask us to explain the information to you. You can talk to anyone from our team whom you feel comfortable with about the research. If after reviewing the information you prefer not to participate, you are free to do so. If you decide to be in this study, you will be one of twenty people who will be interviewed.

Why is this project important?

The purpose of this study is to (1) gain a better understanding of the barriers faced by patients seeking cancer treatment and those faced by providers delivering cancer testing and treatment services in Kenya; and (2) to use this information to formulate policy recommendations that improve access to cancer services in the country.

Who can participate?

There will be twenty participants in this study. 10 clinical officers and 10 non-clinical people who are leaders of organizations representing cancer patients and survivors. You are being

invited to take part in this research as one of the twenty people who will be interviewed by the researcher.

Participation is your choice

Your participation in this research is completely voluntary. You will make the choice about whether you will participate or not.

What is involved in this project?

Participation in this study will take 30-45 minutes of your time. If you agree to be in the study, I will ask you to do the following things:

1. Respond to questions that I will ask you by telephone or a skype call.
2. Accept to receive a follow up call seeking clarification on information provided during the telephone interview within 6 months.

If changes are made to the study or new information becomes available, you will be informed.

No future use of the research data beyond the current study is anticipated. All responses obtained through the interviews will be destroyed after one year of the study's completion. I will ask you questions using a standard questionnaire developed for the study. I will record your responses using an audio recorder which will enable me to accurately capture your responses. No video or photography will be used to identify you or any of the other study participants.

How long will the project last?

This study takes place over a 6 month period.

What are the risks?

There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable talking about some of the topics in this study. However, we do not wish for this to happen. You do not have to answer any question or take part in the survey if you feel the question(s) are too personal or if talking about them makes you uncomfortable.

What are the benefits?

There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve access to cancer testing and treatment in Kenya.

This study is also expected to benefit society by advancing our understanding of the barriers facing the effective delivery of cancer services in Kenya and other countries that could be facing similar challenges. The study would provide information that could support the

Government of Kenya in amending existing the cancer bill and policies; (2) increasing the allocation of resources to address the identified barriers by the governments and private sector; and (3) supporting better implementation in accordance with the country's plans for addressing cancer.

How will we protect your information and confidentiality?

You will remain anonymous and your answers will be confidential. All the information I receive from you including your name and any other identifying information {if applicable}, will be strictly confidential and will be kept under lock and key. I will not identify you or use any information that would make it possible for anyone to identify you in any presentation or written reports about this study. Any information about you will have a number on it instead of your name. Only the researcher will know what your number is and we will store that information securely. If it is okay with you, I might want to use direct quotes from you, but these would only be quoted as coming from "a person" or a person of a certain label or title, like "one woman said." When I finish with all the phone surveys from everyone who has agreed to participate, I will group all the answers together in any report or presentation. There will be no way to identify individual participants. The only risk to you might be if your identity were ever revealed. But I will not even record your name with your responses, so this cannot occur. There are no other expected risks to you for helping me with this study.

What will happen with the results?

The knowledge that we get from this research will be shared with you and your community before it is made widely available to the public. Each participant will receive a summary of the aggregate findings of the study upon request. This study could be published so that other interested people may learn from the research.

Can I refuse to participate or withdraw from the study?

You do not have to take part in this research if you do not wish to do so. There is no cost or payment to you as a participant however, if you have questions while taking part, please stop me and ask. If you wish to stop participating in the study after you begin, you can stop at any time.

Who can I contact?

You can reach me by phone at 0719 251 240, or + 1 484 716 6014, or email (Lmakau@live.unc.edu) with questions about the research study. All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a participant you may contact, anonymously if you wish, the African Medical & Research Foundation (AMREF) Ethics & Scientific Review Committee (ESRC) by email to esrc.kenya@amref.org or The Research Officer, AMREF Kenya, Wilson Airport, Lang'ata Road, Office Tel: +254 20 6994000, Fax:

+254 20 606340 P.O Box 30125-00100 Nairobi, Kenya. You can also contact the UNC Institutional Review Board at +1 919-966-3113 or by email to IRB_subjects@unc.edu.

Do You Have Any Questions At This Time?

Part II: Certificate of Consent

I have read the above information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study by indicating my name below and initials below.

Print Name of Participant	
Signature of Participant (Initials)	
DD/MM/YYYY	

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

- 1. I will contact the participants if needed within 6 months following the interview if I need clarification on their responses**
- 3. The participant's information will be kept confidential.**

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent	LOUISE MAKAU-BARASA
Signature of Researcher/person taking the consent	
DD/MM/YYYY	

APPENDIX 4: KEY INFORMANT INTERVIEW GUIDE

How Can Access to Cancer Diagnosis and Treatment Be Improved In Kenya?

Part I: Clinical Personnel Interview Guide

Hi, my name is Louise Makau-Barasa, a doctoral student at the University of North Carolina's Gillings School of Global Public Health. I am conducting research to understand how access to cancer testing and treatment can be improved in Kenya by identifying barriers faced by providers and patients, and their potential solutions. At least twenty people comprised of medical providers and civil society (NGOs) representing cancer survivors and patients will be interviewed. This interview is expected to take 30-45 minutes and will be completely confidential. You may stop the interview at any time if you so desire. Your name or institution will not be connected to your answer. Your participation is much appreciated. I would like to record the interview with your permission.

This interview is broken into three sections. The first section is seeking information about your practice and your patients, the second about your experiences as a provider, and the third section your thoughts on the effect of current cancer policies and practices on the delivery of cancer testing and

Topic: Characteristics of the health systems delivery and utilization of health services

Section I: I would like to get an understanding of your practice, patients and work volume.

1. Please tell me how long you have been practicing medicine in this community.
2. How would you classify your current practice? *(if necessary probe further- is it private, group based, public, hospital based or a combination of hospital and private practice?)*
3. How many patients do you see per day and are they for cancer or other diseases as well?
4. Where do the majority of your clients/ patients come from? *(note if they indicate urban, peri-urban or rural areas)*
5. Tell me about the demographics of your patients *(level of education, income levels, gender, and average age. Also probe later e.g. if participant mentions costs and how they vary by type of patient)*

6. What is the average time you spend with a patient?
7. How much time do you believe patients/ clients wait to see you or be attended in your practice/ facility?
8. Using your best estimate, at what stage of cancer do the majority of the patients come to see?
9. What percentage of your clients do you believe hear about cancer for the first time when you diagnose them?
10. What kind of information or resources do you have for your patients?

Topic: Organization of health services

Section II: In the following section, I would like to get an understanding of your experiences as a provider delivering cancer services.

1. Tell me about the challenges you face in delivering services to patients.
2. What are the most important factors that you believe influence a patients decision to undertake treatment (if necessary, probe using the list below on the ones they haven't mentioned)
 - a. *Treatment costs*
 - b. *Patient's insurance status*
 - c. *The economic condition of the patient*
 - d. *The age of the patient*
 - e. *Patient opinion*
 - f. *Family opinion*
 - g. *Availability of drugs, equipment and supplies at the treatment facility*
3. Among the patients you treat, who usually decides on the patient's treatment (*circle the answer that is closest to the one their response or ask how much the patient and or family decide on the treatment once a cancer diagnosis is confirmed*)
 - a. *I usually decide*
 - b. *The patient and I decide together*
 - c. *The patient, I and his/ her immediate family members decide together*
 - d. *The patient and her family decide*
 - e. *The patient decides*

4. What do you believe most affects patients' access to your services? (*probe if the participant provides only one word answer*)
11. Are you able to follow-up patients you refer to other facilities or physicians (*probe based on response where they referred to and how the clinician follows up*)

Topic: Health Policy

Section III: In the following I would like to get your opinion on the effect of current policies and practices on your delivery of cancer services

1. In what ways has the Cancer Prevention and Control Act, 2012 affected your practice or profession?
2. What laws or policies at the national level do you believe would improve the delivery of cancer testing and treatment in your community?
3. What type of health facility practices could be implemented to improve the delivery of cancer testing and treatment in your community?
4. Is there anything else that you believe should be known that could improve the delivery of cancer testing and treatment in Kenya?

I thank you for your time. Your responses are invaluable to this study. If you are interested in receiving a copy of this study, please contact me at the following email address:

Lmakau@live.unc.edu

Part II: Non-Clinical Personnel Interview Guide

Hi, my name is Louise Makau-Barasa, a doctoral student at the University of North Carolina's Gillings School of Global Public Health. I am conducting research to understand how access to cancer diagnosis and treatment can be improved in Kenya by identifying barriers faced by providers and patients, and their potential solutions. At least twenty people comprised of medical providers and civil society (NGOs) representing cancer survivors and patients will be interviewed. This interview is expected to take 30-45 minutes and will be completely confidential. Your name or institution will not be connected to your answer. Your participation is much appreciated. I would like to record the interview with your permission. This interview is broken into two sections. The first section is about your group members and their experiences with the current cancer testing and treatment services in Kenya and the

second section is about your opinion on the effect of current cancer policies and practices in Kenya.

Topic: Characteristic of the population at risk and consumer satisfaction (convenience, access to information)

Section 1: I would like to get an understanding of your group members and their experiences with the current cancer testing and diagnosis services provided here (in Kenya)

1. Please tell me about your group members (*probe- their average age, where they come from- urban, peri-urban or rural areas- level of education, employment status, insurance status, income levels*)
2. What types of challenges are reported by your group members when they are seeking access to cancer testing and treatment? (*note the most commonly cited and probe with additional ones if answers are one word*)
3. What kind of information does your group provide to group members?
4. According to your group members, what factors determine whether they undertake treatment or not? (*if necessary, probe using the list below*)
 - a. *Treatment costs*
 - b. *Patient's insurance status*
 - c. *Employment status*
 - d. *The economic condition of the patient*
 - e. *Age*
 - f. *Patient opinion*
 - g. *Family opinion*
 - h. *Availability of drugs, equipment and supplies at the treatment facility*
5. Based on your group member's at what stage did majority of them seek medical care for cancer?
6. Using your best estimate, what percentage or proportion of your group members knew about cancer before their own diagnosis? What were their sources of information?

Topic: Health Policy

Section 2: The following sections is seeking your opinion on the effect of current cancer policies and practices on the access and delivery of cancer services in Kenya

1. In what ways has the Cancer Prevention and Control Act, 2012 affected access to cancer services for patients and survivors?
2. What laws or policies at the national level do you believe would improve access to cancer testing and treatment in your community?
3. What types of practices could be implemented to improve access to cancer testing and treatment in your community?
4. Is there anything else that you believe should be known that could improve access to cancer testing and treatment in Kenya?

I thank you for your time. Your responses are invaluable to this study. If you are interested in receiving a copy of this study, please contact me at the following address:

Lmakau@live.unc.edu

APPENDIX 5: EXAMPLE OF TRANSCRIBED RESPONSES

Based on your group member's at what stage did majority of them seek medical care for cancer?

NCP1: Most people don't just go for screening even after the awareness. They usually come for screening once they get a symptom.

NCP2: Many of our members are perhaps on the higher income bracket...well educated and had insurance which is unusual in Kenya. The ordinary person does not have this. Many of our members got assistance in good time but we also have many case of late stage cancer... and it is very depressing.

NCP3: Unfortunately, most cancers we're finding are in the late stages. Stage 3, 4. This is why we advocate for people to be aware and seek annual screening... we realize that the medical personnel are really stretched. And so, if someone comes with a recurrent stomach ache they prescribe antacids or whatever else they give and it may take a while before they actually send you for the correct tests and that's the problem. So we want to empower the people so that they have health seeking behavior.

NCP4: Generally speaking, in the later stages. This is because of the factors I shared with you. You know, lack of money, lack of knowledge, not grasping the gravity of the situation. They present only when the signs and symptoms are such that they don't have much of a choice but to actively seek medical attention.

NCP5: Sadly about 80% seek attention when it's very late. And that's why Makau, I'm very aggressive about awareness.

And late being which stage? Three, four. Like when I was diagnosed I started taking data. When I meet a patient I take their names down. Within a year I think I had 25 names. Out of which 10 had died in less than 6months. I realized this is going to wear me out, demoralize me so I stopped because I was scared. I lost 2 of my very close friends by virtue of the same. One of them is a lady we started this thing with and even went to training in Cape Town with, when we came back, she didn't make it through October. So yes more than 80%. Theres a lady we went to visit with a late friend and colleague of mine. She was on GNLD

supplements and had adamantly refused treatment. She told the husband no hospital. She ended up going to hospital because of a fracture. The doctors in the course of investigating the fracture found the cancer and informed her. She was still adamant until we were called and spoke to her. Even with us she was not receptive. We had to close the curtains and showed her our breasts. She was shocked and that's the point she acknowledged what she had because she saw there was hope after the diagnosis after looking at us. This is when she told us her story of how she had refused to listen to her husband and get treatment earlier on and instead turning to supplements. And of course now it was quite late stage 4. So again, it is individual. There is another 'cucu' we saw her when she was 70. Now she must be around 78. She was very open to what we told her but then again she could have just said she's old and doesn't want to go through it. So, it is individual."

NCP6: For the people in our groups, I can say 70% of the cases went to the doctors when the cancer was advanced mostly with the cervical cancer cases. I can say that it also has to do with their economic situation because those who have money go for annual checkups and whereby the prostate cancer can be diagnosed early but for those who do not have funds...they come when it is late stage. Sometimes it is nothing to do with finances but the doctors who misdiagnosed them. We have so many people being taken around in circles by the doctors – general practitioners who did not know that it was cancer. So many are complaining that if they knew earlier or were diagnosed earlier, their cancer would have been treated. You are told you have a sore throat and the doctor does not look at the issue keenly.

NCP7: Most of them are at the stage 2 when the symptoms start presenting themselves and some at pre-cancer stage and stage 1.

APPENDIX 6: KENYA’S LEGISLATIVE PROCESS⁶⁷

1. First Reading

A first reading is when a bill is introduced to a legislature by a Member of Parliament (MP), Senator or Governor. Typically, the bill is assigned a tracking number and immediately assigned to a committee. In most British influenced legislatures (Westminster systems) such as Kenya’s, the committee consideration occurs between second and third readings.

2. Second Reading

A second reading is the stage of the legislative process where a draft of a bill is read a second time. In most Westminster systems, a vote is taken in the general outlines of the bill before it is sent to the designated committee.

3. Third Reading

A third reading is the stage of a legislative process in which a bill is read with all amendments and given final approval by the legislative body. In legislatures whose procedures are based on those of the Westminster system, the third reading occurs after the bill has been amended by the designated committee.

4. Presidential Assent

The granting of Presidential Assent is the formal method by which the head of the Executive arm of government completes the legislative process by formally assenting or giving his consent to an Act of Parliament.

5. Commencement

Quite often, an Act of Parliament may provide that it will come into effect on a date to be notified. In such cases, after the Act has received Presidential Assent, notification of the

date of its coming into effect is given through a legal notice usually by the Minister for the time being in charge of the matters with which the Act is concerned.

6. Financing⁶⁸

8 —Except upon the recommendation of the President signified by a Minister, the National Assembly shall not-

(a) proceed upon a Bill (including an amendment to a Bill) that, in the opinion of the person presiding, makes provision for any of the following purposes-

(i) the imposition of taxation or the alteration of taxation otherwise than by reduction; or

(ii) the imposition of a charge on the Consolidated Fund or any other fund of the Government of Kenya or the alteration of any such charge otherwise than by reduction;
or

(iii) the payment, issue or withdrawal from the Consolidated Fund or any other fund of the Government of Kenya of moneys not charged upon the fund or an increase in the amount of the payment, issue or withdrawal; or

(iv) the composition or remission of a debt due to the Government of Kenya; or

(b) proceed upon a motion (including an amendment to a motion) the effect of which, in the opinion of the person presiding, would be to make provision for any of those purposes.

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