

# **ECONOMIC AND SOCIAL CONSEQUENCES OF CANCER IN KENYA *CASE STUDIES OF SELECTED HOUSEHOLDS***

DISCUSSION PAPER

MAY 2020

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**WORLD BANK GROUP**  
Health, Nutrition & Population



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*Case Studies of Selected Households*

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## Health, Nutrition Population (HNP) Discussion Paper

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# Health, Nutrition and Population (HNP) Discussion Paper

## Economic and Social Consequences of Cancer in Kenya: Case Studies of Selected Households

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### EXECUTIVE SUMMARY

The burden of noncommunicable diseases (NCDs) in Kenya is rising rapidly, and now accounts for more than 50 percent of all hospital admissions, and nearly 30 percent of total deaths. Cancer is the second-leading cause of NCD mortality in Kenya, with its the incidence nearly doubling between 2008 and 2012. The illness affects Kenyans of all ages and socioeconomic backgrounds, and presents an increasing risk as age progresses. Most cancer cases are diagnosed at an advanced stage when treatment options are limited, leading to high out-of-pocket (OOP) spending, poor prognosis, and high fatality rates. Households not covered by health insurance are among the most vulnerable to health shocks, often forced to adopt coping strategies like borrowing or selling assets, with potentially long-term ramifications on livelihoods.

In recent years, substantial progress has been made in mitigating the economic burden of cancer care for patients. Kenya has developed a cancer control plan, established population-based cancer registries; and is expanding access to cancer screening, diagnosis, and treatment. In 2015/16, the National Hospital Insurance Fund (NHIF) introduced cancer care as part of the outpatient benefit package and announced further expansion with a comprehensive cancer care plan based on new protocols developed by the National Cancer Control Programme. All these efforts are in line with the Kenya National Cancer Control Strategy (2017–2022), which underscores the need for universal coverage of cancer services.

This report uses a case study approach with focus group discussions (FGDs) and in-depth interviews to shed light on the patient journey, and better understand the direct and indirect costs families face; the difficult decisions and choices they need to make; and the socioeconomic and psychological implications of having a family member afflicted by cancer. The report summarizes findings from in-depth interviews with eight households selected based on maximum variation sampling; two focus group discussions conducted with a total of 16 participants from Nakuru (seven women) and Kisumu (three men, six women) counties; and interviews with eight experts on cancer policy, treatment, and financing.

The report follows the lives of eight cancer patients and highlights experiences and lessons from their respective battles along the cancer journey. Some major themes that emerged through the personal narratives include (i) lack of awareness and poor knowledge of cancer and late health-seeking behavior; (ii) difficulties in navigating the health care system and delays in getting an accurate and timely diagnosis; (iii) inadequate health insurance coverage and gaps in the benefit package, which limit access to critical diagnostic tests, treatments, and drugs; and (iv) sociocultural barriers, including stigma, fear, and myths that impede patients from seeking care early. Other themes that emerged relate to the (i) potential impact of social safety nets to mitigate the impact on patients and households; (ii) importance of cancer survivor groups to provide support; and (iii)

resilience of cancer patients as they embark on the road to recovery. The personal narratives are categorized to illustrate challenges along the cancer journey.

Analyses of the economic and social impact of cancer found that most patients/households suffered economic losses due to lost wages, sold assets, and in some cases growing debts, as well as significant medical and nonmedical spending on cancer care. Most patients were not enrolled in the NHIF at the time of the diagnosis, but the majority enrolled subsequently and benefitted from coverage for high-end treatments such as radiotherapies or chemotherapies and surgeries. However, some patients still incurred significant out-of-pocket costs, as drugs and diagnostics have limited coverage under the NHIF and nonmedical care costs (e.g., transportation and accommodation) accounted for one-fifth of cancer-related costs for patients.

The report identifies factors that influence a patient's journey and proposes a series of recommendations to mitigate the cost of cancer to patients and families. Factors that influenced a patient's cancer journey included formal employment and asset ownership; social and cultural norms; gender of the patient and caregiver; opportunity and access to support; access to the NHIF; and decisions made by the household. Key recommendations moving forward include expanding the coverage of NHIF benefit package and social security nets; reducing information asymmetries and improving the quality of care; strengthening early detection, screening, and diagnosis at the primary health care delivery level; using evidence-based approaches to care; and conducting additional research on the cost of cancer and on gender-related aspects of cancer care.

**Keywords:** cancer, late-stage diagnosis, high out of pocket spending; risk of impoverishment

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## ABSTRACT

The burden of NCDs in Kenya is rising rapidly, and now accounts for more than 50 percent of all hospital admissions, and nearly 30 percent of total deaths. Cancer is the second leading cause of NCD mortality in Kenya, with the incidence of cancer nearly doubling between 2008-2012. The illness affects Kenyans of all ages and socio-economic backgrounds, with an increasing risk of cancer as age progresses. Most cancer cases are diagnosed at an advanced stage when treatment options are limited, leading to poor prognosis and high fatality rates.

This report uses a case study approach with focus group discussions and in-depth interviews to shed light on the patient journey, and better understand the direct and indirect costs families face; the difficult decisions and choices they need to make; and the socio-economic and psychological implications of having a family member afflicted by cancer.

Key challenges identified include lack of awareness and poor knowledge of cancer; late health seeking behavior; inadequate health insurance coverage and gaps in the benefit package which limit access to critical diagnostic tests, treatments and drugs; and socio-cultural barriers, including stigma, fear and myths that impede patients from seeking care early. The main themes from the patient stories and focus group discussions, including the economic impact on patients and households are summarized and a series of recommendations to mitigate the cost of cancer to patients and families are proposed based on the findings from the case studies.

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Joel Lehmann and Yvonne Wangūi Machira oversaw the research and qualitative analysis, including the coordination of focus group discussions and participant interviews. This report is a summary of the detailed qualitative report written by the main authors. Miriam Schneidman and Jane Chuma contributed to the synthesis of the original report; Liying (Annie) Liang provided valuable editorial and statistical support; and Yvette Atkins supported the finalization of the report.

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*\*Note: The photos shown in this report were taken by Yvonne Wangūi Machira. All study participants and/or their respective families provided explicit written consent for use of their photos. The names of patients have been changed before publication to protect their identities*

## BACKGROUND: TACKLING THE BURDEN OF CANCER IN KENYA

**With aging populations, sedentary lifestyles, improved control of communicable diseases, and rapid urbanization, more and more developing countries are faced with the rising challenge of noncommunicable diseases (NCDs) as major contributors to death and disability.** Noncommunicable diseases kill 41 million people each year, equivalent to 71 percent of all deaths globally. NCDs are projected to represent the leading cause of death in all countries irrespective of income level (WHO 2018a). Sub-Saharan Africa is among the regions projected to experience the largest increase, with NCDs expected to account for 46 percent of all deaths by 2030. NCDs affect people in their most economically productive years, and are major contributors to premature deaths, with over 85 percent of these premature deaths in low- and middle-income countries (LMICs) (WHO 2018b). NCDs lead to significant economic losses due to decreased productivity, lost wages, and catastrophic health spending.

**Like in many low- and middle-income countries, the burden of NCDs in Kenya is rising rapidly.** NCDs now account for more than 50 percent of all hospital admissions, and for nearly 30 percent of total deaths. According to the STEPwise approach to surveillance (STEPS) Survey for NCDs 2015, the prevalence of adult risk factors for NCDs is high, and comparable or even higher than in other LMICs. Almost one in three Kenyan adults has high blood pressure and a similar number are overweight, with women disproportionately affected by these chronic conditions.

### HIGH LEVELS OF MORTALITY: LOW AWARENESS, LATE-STAGE DIAGNOSIS

**Cancer is the second-leading cause of NCD mortality in Kenya with the incidence of cancer nearly doubling between 2008 and 2012** (Subramanian et al. 2018). The illness affects Kenyans of all ages and socioeconomic backgrounds, and presents a higher risk as age progresses. The annual number of new cancer cases in Kenya is roughly 41,000, with cervical cancer leading (11.7 percent), followed by breast cancer (10.9 percent), Kaposi's sarcoma (9.4 percent), and esophageal and prostate cancer (8.4 percent and 6.2 percent, respectively). Only 11 percent of Kenyan women have ever been screened for cervical cancer, highlighting low levels of awareness and knowledge, as well as limited availability of early screening and detection in primary health care settings.

**Most cancer cases are diagnosed at an advanced stage when treatment options are limited, leading to poor prognosis and high fatality rates** (Kenya, MOH 2013). For example, nearly 60 percent of breast cancer cases and 47 percent of cervical cancer cases are diagnosed at stage III or IV, when the only viable treatment option is palliative care. As a result of late health-seeking behavior and late-stage diagnoses, mortality remains persistently high. During 2008 to 2012, mortality rates among cancer patients were 44 percent for breast cancer, 51 percent for cervical cancer, and 92 percent for esophagus cancer among female patients, and 81 percent for prostate, 90 percent for esophageal, and 92 percent for stomach cancer among male patients.<sup>1</sup>

### RISK OF IMPOVERISHMENT: MORTALITY NUMBERS ALONE DON'T TELL THE FULL STORY

**The cost of health care in Kenya weighs heavily on households and can lead to impoverishment.** The economic burden of out-of-pocket (OOP) spending is inversely related to the economic status of households, with the poorest quintile spending on average 15 percent of their budget on health care, while the richest quintile spends on average 2 percent. Only 20 percent of the Kenyan population had health insurance coverage in 2018, with the National Hospital Insurance Fund (NHIF) covering a limited package of inpatient and outpatient cancer services (Kenya, MOH 2018). According to the 2018 Kenya Household Health Expenditure and Utilization Survey, 8 percent of all Kenyan households experienced catastrophic health expenditures, and OOP payments push about 1.1 million Kenyans into poverty annually (Salari et al. 2019). Relative to other

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1. These mortality rates are derived from data from Nairobi and Uasin Gishu County.

illnesses, NCDs have a higher negative impact on overall household spending, reducing household income by 29 percent in contrast to 14 percent for general illnesses (Mwai and Muriithi 2016). While the cost of screening for cancer is relatively inexpensive, the cost of diagnostic procedures is substantially higher. For breast cancer, multiple diagnostic tests that cost an average of US\$401 per test in public facilities and US\$1,205 in private facilities, are needed—far above the US\$413 total annual household expenditures per adult. Inpatient treatment costs per episode range from \$1,340 (public sector) to \$10,914 (private sector) for stage I/II breast cancer, and from \$1,542 (public sector) to \$11,862 (private sector) for stage III breast cancer, rendering cancer services unaffordable for large segments of the population (Subramanian et al. 2018). Households not covered by health insurance are among the most vulnerable to health shocks. Households are often forced to adopt coping strategies like borrowing or selling assets, with potentially long-term negative impacts on livelihoods.

## **MITIGATING THE ECONOMIC BURDEN OF CANCER CARE FOR PATIENTS**

**In recent years, substantial progress has been made in expanding the NHIF benefit package, including selective interventions related to NCDs.** In 2015/16, the NHIF introduced cancer care as part of the outpatient benefit package. At the time of data collection for this study, the NHIF coverage for cancer treatment included radiotherapy, chemotherapy, and surgery, as well as renal dialysis, up to a predetermined limit. In early 2019, the NHIF announced plans to replace the undifferentiated oncology coverage plan with a comprehensive cancer care plan, based on new protocols developed by the National Cancer Control Programme. The new package is expected to address a range of gaps in the benefit package. In addition to the inclusion of additional laboratory tests and follow-up specialist consultations, it is expected to include enhanced coverage of nutrition support, psychological counseling, and palliative care. However, the time line for the expansion of the cancer care package remains unclear. The Ministry of Health has also launched comprehensive guidelines on cancer screening for health workers and the public, including recommendations in favor of early diagnosis for nonscreenable cancers. To further strengthen health promotion and prevention, the Ministry of Health, has been developing a universal health care (UHC) benefit package that emphasizes the need for early screening and detection of NCDs, including cancers. All these efforts are in line with the Kenya National Cancer Control Strategy (2017–2022), which underscores the need for universal coverage of cancer services.

**Kenya's efforts on cancer control is setting an example of what is possible in a resource-constrained, limited-capacity setting in Sub-Saharan Africa (SSA).** Kenya has developed a cancer control plan; established population-based cancer registries; and is expanding access to cancer screening, diagnosis, and treatment. Five new cancer centers are planned outside of Nairobi, and health care workers are being trained to detect cancers at the community level (Anderson 2019). With only 22 oncologists for a population of 46 million people, Kenya is also accelerating training of critical health care workers, including fellowship programs in medical and gynecological oncology, and a radiation oncology master's program established at the University of Nairobi. Moreover, Kenya is one of the first countries in SSA to set up a wide network of palliative care centers, integrating palliative care into many level 4 and 5 hospitals, and making available oral morphine in hospital palliative care units. Despite these advances, there are still many gaps in cancer care. The next section describes key challenges patients face.

## **PATIENT CHALLENGES IN ACCESSING CANCER CARE**

**One of the key challenges is lack of awareness and poor knowledge of NCDs, including cancer, which leads to late health-seeking behavior with large socioeconomic and gender disparities.** Only 22 percent of the poorest have heard of cervical cancer screening in comparison to 61 percent of the best off. Likewise, only 11 percent of Kenyan women have ever been screened, yet cervical cancer is one of the leading cancers affecting women. Although screening for cervical and prostate cancer is covered under the NHIF, lack of awareness of the benefits of

early screening coupled with limited availability (i.e., gaps between the package on paper and in practice) result in low uptake among members.

**A second set of challenges relates to gaps in the benefit package.** Coverage of critical diagnostic tests, treatments, and drugs is limited. NHIF coverage in 2019 included reimbursement of K Sh 25,000 (US\$250) per chemotherapy session for up to 6 sessions per financial year; K Sh 18,000 (US\$180) per week for radiotherapy sessions for up to 20 sessions in total; and up to K Sh 500,000 (US\$5,000) for surgery.<sup>2</sup> NHIF does not cover palliative care, psychosocial counseling, and the newest cancer therapies (i.e., monoclonal antibodies, biologics, and personalized medicines), which are expensive and unaffordable for most Kenyans. Furthermore, a fixed maximum coverage for cancer services with no provision for the variations in cancer types and treatments has left households with substantial out-of-pocket spending. Given that individuals do not always enroll in the NHIF when healthy, the 60-day waiting period becomes problematic for patients who enroll when they are in need of urgent care. In addition to gaps in the benefit package, patients and families struggle with the substantial financial burden of nonmedical costs including transport, lodging, and special food.

**A third set of impediments relate to financial and sociocultural barriers.** Financial barriers remain important, given the high cost of cancer care and low insurance coverage. Likewise, sociocultural barriers, including stigma, fear, and pervasive myths around cancer impede patients from seeking care early.

**Another key issue facing cancer patients is the inadequate availability and quality of care.** Health system capacity remains modest and concentrated primarily in a few urban centers. Shortages of pathologists, oncologists, and other specialists hinder the ability of facilities to provide diagnostic and treatment services. Inaccurate cancer diagnoses and poor quality of care is costly for patients, and can lead to long, convoluted journeys before patients receive an accurate diagnosis. Communication skills of health care professionals are critical to helping patients access services and remain compliant to treatment protocols. Mixed messages and poor bedside manner can contribute to the psychological burden, and lead to suboptimal decision-making by patients and their families with respect to treatment options.

**Behind each cancer figure is a person and a family struggling to cope with the medical and socioeconomic consequences of a disease that affects individuals in the prime of their lives.** This small qualitative study aims to make a modest contribution to the broader efforts underway to improve access to cancer care. To understand what kind of support is needed, a closer look at the experiences of patients and their families can provide useful insights to public and private providers, employers, and civil society.

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2. See Annex I for the NHIF Oncology Package, as of November 2018.

## STUDY DESIGN AND METHODOLOGY

### STUDY RATIONALE

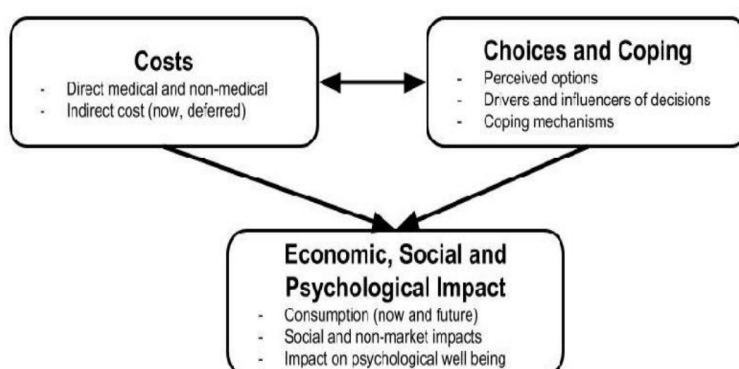
This study aims to shed light on the patient journey to better understand the direct and indirect costs families face; the difficult decisions and choices they need to make; and the socioeconomic and psychological implications of having a family member afflicted by cancer. There is limited research in Kenya examining the cost and impact of diseases at the household and patient level, relative to their impact on the health system. The only study identified that assessed the cost of NCDs at the household level was a paper published by Subramanian et al. in 2018, which studied the direct medical costs for treating cervical and breast cancer in public and private facilities and found that the medical costs of treatment are greatly dependent on the stage of diagnosis and whether a curative or palliative approach was adopted (Subramanian et al. 2018). There are also important indirect costs such as lost income; averted savings due to sickness and premature death; deferred costs associated with decreased investment in a child's education; and nonmarket impacts including reduced household production, fewer leisure activities, and lower investments in human capital. The socioeconomic situation of the household such as income level, assets, and social support mechanisms influence the risk of impoverishment (WHO 2009).

**Households with a cancer patient face many difficult choices.** Decisions are often taken in a highly emotional context, in a situation of physical pain and great uncertainty about the prospect of treatment success. Patients and family members must decide about treatment approaches, selling assets, taking out loans, and cutting back on spending. The choice of treatment is particularly sensitive, as both undertreatment and overtreatment are risky and costly in different ways. Given information asymmetries, it is challenging for households to assess both the consequences of these choices and the costs of inaction.

### CONCEPTUAL FRAMEWORK

The study uses the conceptual framework below to get a better understanding of patient experiences by focusing on the (i) *direct and indirect costs* associated with cancer; (ii) *coping strategies* adopted; and (iii) *consequences* in terms of consumption, nonmarket impacts, and social and human capital (Figure 1). While the health impact is not part of the conceptual framework, it is important to address the delayed health-seeking behavior and late-stage diagnosis, which often lead to poor outcomes. More details on each of the aspects below are included in Annex I.

Figure 1. Conceptual Framework Adopted for the Study



Source: Authors.



## METHODOLOGY

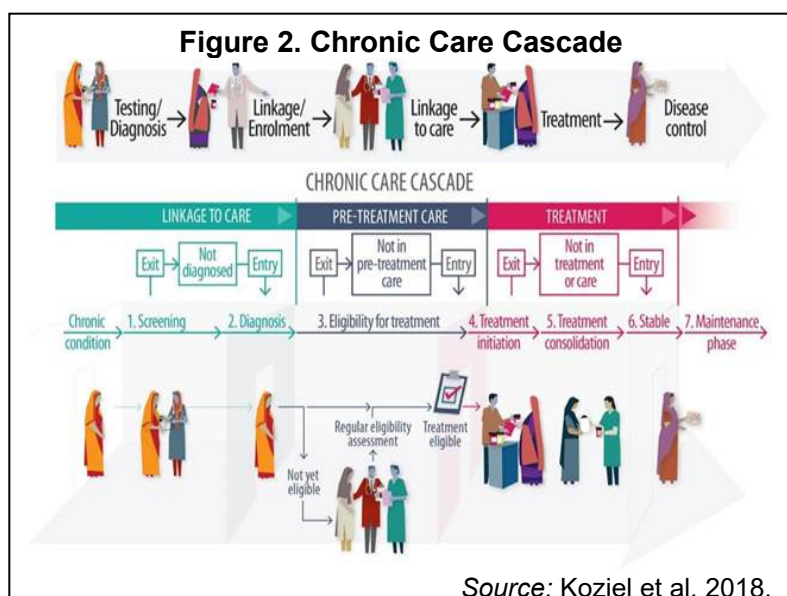
**A case study approach was used to gain a better understanding of the experiences of cancer patients and their families.** The approach allows for the personal perspective of individual patients, documenting their coping mechanisms, the costs incurred, and the economic impact of the illness. The approach does not seek to capture all costs with precision. Instead, it provides an indication of orders of magnitude. The study involved two focus group discussions (FGDs) conducted with a total of 16 participants from Nakuru (seven women) and Kisumu (three men, six women) counties to identify the overarching themes; in-depth interviews with eight households selected through maximum variation sampling; and interviews with eight experts on cancer policy, treatment, and financing. The study includes households that experienced a cancer episode both before as well as after the expansion in the NHIF benefit package to better understand risks of impoverishment and the benefits of financial protection. More details on the methodology (including the characteristics of focus group participants) are included in Annex II.

### Methodological Limitations

**The study has several limitations.** *First*, the study involves a small sample size and is qualitative in nature. These are personal testimonials that may have an anecdotal nature. Hence the findings from the case studies are not readily generalizable, so results should be used accordingly. *Second*, recall bias is another limitation, as patients and family members who are either sick or distraught may not be able to accurately share all costs incurred or to recall the exact time frame during which the costs were incurred. *Third*, given that most patients were engaged in informal sector work, it was not easy to accurately ascertain monthly incomes. *Finally*, the small sample size and purposeful selection of a wide range of patients with different cancers limits the robustness of the cost information, as costs incurred were not comparable, given the variation in the stage of diagnosis, the type of cancers, and the availability of financial protection. Despite these limitations, the issues and findings that emerged highlight common themes, which need to be better understood and addressed.

### Study Outline

The remainder of this report is divided into three sections. The first describes the cancer journey from a patient's perspective. It includes personal stories of cancer patients, describing the challenges they faced in getting an accurate and timely diagnosis, securing funding for treatment, and accessing quality cancer care. The personal narratives are categorized to illustrate challenges along the patient's journey (Figure 2), from first, seeking care and ensuring timely diagnosis; second, navigating the health care system; third, minimizing risk of impoverishment and tapping social safety nets; and finally, confronting posttreatment challenges. The main themes from the patient stories and focus group discussions are summarized. The second section describes the economic impact on patients of a cancer diagnosis as well as factors that influence the patient's experience with cancer, drawing on the case studies. The third section provides a series of recommendations to mitigate the



Source: Koziel et al. 2018.

cost of cancer for patients and families.

## IN THE FOOTSTEPS OF A PATIENT'S CANCER JOURNEY

### AWARENESS AND ACCESSING CARE: PROVIDING CLEAR HEALTH MESSAGES

#### GRACE

In the kitchen of a small two-room house, Grace was busy preparing chai (tea) to welcome her visitors. “No business can be conducted until my guests have had sufficient chai and buttered bread,” she said cheerfully. As Grace fluttered around the tiny kitchen, which doubled as an additional sleeping quarter, a flash of pain pierced briefly through her otherwise serene face.

Grace’s cheerful disposition masked decades of pain grappling with her ex-husband’s alcoholism, their separation, and her recent breast cancer diagnosis. Grace’s older brother, a warden at the Kakamega Prison, hovered protectively close by. His imposing figure juxtaposed against the obvious tenderness he felt toward his younger sister was particularly touching. He was her main chaperone through the worst periods, not only helping to cover medical costs but occasionally accompanying her to strenuous medical appointments.

As a 45-year-old single mother to five children ranging from 14 to 27 years, Grace made a living selling vegetables at the local market, supplementing her meagre income by doing laundry and odd household jobs. In 2017, Grace discovered a painless mass in her right breast. Concerned, she made the 80-kilometer journey to the Kakamega County Hospital, where she was told that the mass needed to be removed but not that it was potentially cancerous. *“They wanted to operate, but they didn’t tell me I had cancer. I didn’t want to [have the surgery] because I heard from others that if you are operated that’s when it spreads more.”*

Without NHIF coverage or enough information, having surgery was neither a decision to be taken easily nor one that was financially feasible for a *mama mboga* (a female vegetable hawker). Grace received conflicting advice from family and friends, with some voicing concerns that surgery would in fact worsen the condition. Even more confusing was that an ultrasound, performed at a private facility, suggested that the mass was not something to worry about. Grace decided to wait.

Within months, the pain became incapacitating. Grace could no longer work or do basic household tasks. The family pooled together money to help cover living expenses, and a joint decision was made to seek a second medical opinion. Grace made the trip to the Moi Teaching and Referral Hospital (MTRH) in Eldoret for further tests, including an ultrasound, three CT scans, and two hemograms. In July 2018, she was *diagnosed with stage II breast cancer*. By that time, the breast mass had ruptured into a festering wound, and the cost of medications to manage the pain was financially out of reach.

Grace’s medical costs were covered by a nongovernmental organization (NGO), the NHIF, and family remittances. At the time of the interview Grace had enrolled in the NHIF. Shortly thereafter she started treatment at MTRH and completed six chemotherapy sessions funded through the NHIF.

Grace expressed hope in the future. “God,” she prayed softly, *“will help me cope with this disease.”*

Grace's story highlights several key themes that emerged from other case studies and the focus groups.

- *Lack of proper communication from health care providers represents a major impediment to taking timely decisions.* Mixed messages not only delay health-seeking behavior but can fuel health care costs as patients consult multiple providers. The theme of poor communication by health care professionals and the avoidance of “*breaking a cancer diagnosis*” was cited by numerous patients, survivors, and household members as a major source of confusion and anxiety. Families affected by cancer are often paralyzed by emotional distress, uncertainty, and lack of clear information around advantages and disadvantages of different options. In some circumstances, a decision must be made quickly due to a deteriorating health situation; hence, access to accurate information is critical.
- *Family and friends play a critical role in supporting cancer patients and hence need to be well-informed.* Family and friends help patients take critical decisions about whether to pursue treatment, which facility to access, how to cope with financial costs, and when to enroll in the NHIF. For patients with well-informed, strong, functional family structures, decisions around financing and fundraising (*harambees*<sup>3</sup>) are often made collectively by the family unit. Well-intentioned family and friends who are not fully informed, can lead patients in the wrong direction; hence, it is important to raise awareness more broadly beyond health care professionals.

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3. *Harambee* is a Kenyan tradition of community self-help events (e.g., fundraising or development activities).

## LINKAGE TO CARE: NAVIGATING THE HEALTH CARE SYSTEM

### JOHN

*“I’m definitely a city boy,”* John jokes, his laughter rumbling off the walls of the family home in Shikangania Village, Kakamega County. John, a jovial 58-year-old father of nine, has lived his entire life among the hustle and bustle of Kakamega Town.

John was a construction contractor and took great pride in his work. He coordinated large-scale construction projects throughout western Kenya. His success was evident in the size of the family home, which featured a cacophony of household sounds and happy voices of six children and eleven grandchildren who shared the home.

But all that ended with the prostate cancer diagnosis. His wife of 38 years spoke up, a hint of resentment in her voice. *“I got so mad at him,”* she said. *“All the times I’ve thought about how his cancer must have been a result of unfaithfulness.”*

John’s cancer journey began with a persistent lower abdominal pain. As he had been healthy his entire life, John didn’t take the pain too seriously and bought painkillers from the local pharmacy. In the nearby Mukumu Hospital, John was tested for HIV and found to be negative.

Upon a friend’s recommendation, John had an X-ray and an ultrasound at a private health facility and was suspected to have gallstones. A second X-ray done at the Kakamega County Hospital was inconclusive. As John’s health deteriorated and the pain got progressively worse, a friend suggested he have a magnetic resource imaging (MRI) test and offered to pay for it. John refused, as he did not feel the cost was justified. After all, he was still able to work, managing the pain with medication and moving around with the aid of a *boda boda* (taxi motorcycle).

One day, as John arrived home from work, a neighbor saw him collapse as he tried to get off the *boda boda*. Promising to help, the neighbor sent a traditional healer to visit John. By the time the healer arrived, however, John was numb from the waist down. The traditional healer suspected he had a kidney ailment and recommended medicines that promised to heal him. *“The herbalist gave me the medication ... but instead of making me better the drugs were causing more pain.”*

Soon John was bedridden. A cousin advised a visit to the Jaramogi Oginga Odinga Teaching and Referral Hospital and drove him there. In Kisumu, John was admitted for a month while CT scans and laboratory tests were carried out and a biopsy sample was sent to the Aga Khan Hospital, one of the few facilities with pathology capacity. Two weeks later, John was diagnosed with stage IV prostate cancer.

Despite the doctor’s recommendation, John declined to be admitted. He found the hospital admission in Kisumu to be expensive and not very efficient and returned to the Kakamega County Hospital for chemotherapy. He waited for his NHIF membership to mature, and subsequently waited to receive treatment, as the hospital was facing drug stockouts.

Even in sickness—despite being unable to stand or walk without support—John was larger than life and constantly surrounded by family. His warm personality and humor radiated like sunlight over everyone. After all, as John would say, *“Laughter was the very best medicine.”*

A few weeks after the interview, John succumbed to cancer.

## MARY

Swahili villages and residential guesthouses dot Kilifi County's sleepy coast. The small village of Vipingo, located about 30 kilometers north of Mombasa, is known for its tranquil lagoon waters, sandy white beaches, and lush coastal forests.

Mary's home sits inside the Swahili village of Vipingo. Modest in size, it houses both her immediate family and a small outdoor shop selling basic goods. Papa Dogo, Mary's husband, is a retired seaman, who has spent his days in the shop after a roadside accident left him partially paralyzed and unable to fish.

Mary immediately broke into a smile at the sight of her visitors. Although only 50 years old, her fragile stature and hunched, tired figure masked her age. As she lay on the bed, Papa Dogo doted over his wife, making sure she was comfortable. The love they have shared during their 37-year marriage was evident even to outsiders.

In 2016, Mary began to experience heavy menstrual bleeding that continued for extended periods of time. Embarrassed, she hid the problem from the family for almost a year, using blankets to stanch the blood flow. While frequent and extended trips to the latrine did not go unnoticed by her daughter-in-law, the family only realized the full extent of the condition when she was no longer able to work in the shop for fear that any physical activity would worsen the bleeding and pain. Friends and relatives gossiped about the condition, and how frail she had become. In shame, Mary stopped all social interactions and refused to leave the house.

Over the course of the next few years, Mary's family visited various health practitioners and traditional healers, trying desperately to understand the cause of the bleeding. At the intervention of a local community organization, *Mulika Saratani* (Light Up Cancer), Mary was first sent to Kilifi County Hospital, then referred for X-rays to a private hospital in Mombasa, and then referred to Coast Provincial General Hospital. There, the doctor on call did not provide a diagnosis but urged her to go to the Kenyatta National Hospital in Nairobi.

Frustrated, the family decided to take Mary to another private facility in Mombasa. In hushed whispers, the doctors exchanged views about the diagnosis and noted that some patients "*can only be treated by God.*" There, Mary was informed that she had cervical cancer. The only option left was a referral to Nairobi.

But there was not enough time or money. To travel to Nairobi would cost the family an estimated K Sh 100,000 (US\$1,000) in transportation, accommodation, and out-of-pocket costs for immediate treatment, as the family had not enrolled in the NHIF. The family shop was struggling as Mary was unable to work, and her husband was frequently away attending to her. Money that would have been used to restock goods was now used to pay for diagnostic procedures, transportation, and treatments. Mary's husband lost his sole mode of transport when he sold his bicycle to finance the taxi fare for a single journey to the hospital.

The cancer diagnosis resulted in large costs associated with multiple diagnostic procedures, traditional healers, and drugs, with most costs incurred to secure an accurate diagnosis, all covered out-of-pocket. Plans to enroll in the NHIF and to fundraise did not materialize, as the late-stage diagnosis took Mary's life.

At the end of the interview, Mary paused, frowning as if trying to grasp at a memory located in a faraway past. Her silence weighed heavily in the room.

Ten days after the interview, Mary peacefully succumbed to cancer.

The two stories above highlight several key themes from other patients and focus group participants:

- *Cancer patients express concerns with the challenges of navigating the health care system that is not well-equipped to provide accurate, timely, and quality diagnoses.* Some patients opt for traditional healers who may promise miraculous cures and can charge exorbitant fees. Others purchase drugs at local pharmacies to deal with infections and related illnesses. Many first go to local hospitals in their catchment areas and are referred to county or private hospitals or to Nairobi, where the main cancer care public sector capacity exists. Multiple visits and repeated tests add to the cost of cancer care and fuel delays in getting an accurate diagnosis and in initiating treatment. Both stories underscore the challenges patients can face when seeking care, and the ramifications of such delays in terms of piling bills stemming from multiple procedures (e.g., pathology, fine needle biopsy aspirations) and/or misdiagnoses, and indirect costs (transportation, living expenses), which can represent a large barrier to accessing urgently needed services not available locally. In both personal testimonials, multiple visits to several public and private health facilities were required before the patients could receive an accurate diagnosis. Given the late-stage diagnosis in both cases, the prospects were not favorable, with both patients incurring large costs before succumbing to the disease.
- *Sociocultural factors also impede a patient's ability to access the health system promptly.* Based on various accounts of patients, survivors, household members, and experts, it appears the fear of stigma from a cancer diagnosis (especially for reproductive cancers), may lead patients not to discuss their conditions or to seek health care. While women diagnosed with cancer are often seen as “bewitched by supernatural forces” in some sociocultural settings, reproductive cancers for both genders are perceived to be a “divine punishment for acts of infidelity.” In Mary’s case, embarrassment related to menstrual bleeding caused her to hide the condition and delay seeking care.
- *Health-seeking behavior is also influenced by the nature of social support mechanisms.* The two personal stories as well as the focus group discussions highlight both the feelings of solidarity and support from families for some fortunate patients, as well as loneliness and isolation for other patients. In John’s case, his gregarious nature and strong relationships at the local church played a crucial role in seeking care, helping cover costs, and providing emotional support through the cancer journey. Community members provided a strong social safety net with close friends pooling resources to pay for his children’s school fees, allowing them to stay in school. By contrast, in Mary’s case, embarrassment resulted in severe depression and late health-seeking behavior.

## ACCESS TO TREATMENT: RISK OF IMPOVERISHMENT AND SOCIAL SAFETY NETS IN TIMES OF NEED

### WINNIE

Winnie's cancer journey is told by her 50-year-old daughter, Mercy, who was the primary caregiver in a family of 10 siblings. The illness and demise of her mother changed Mercy's life. *"My mother, Winnie, was liked by everybody, and was so kind,"* Mercy said with a sigh. *"She was a farmer who worked daily with makuti [dried palm leaves used to make baskets and brooms] and enjoyed spending time with her grandchildren."*

Mercy, a single mother of three sat quietly on the bed, in a small room shared with her two sons. Only a few years earlier, they had all lived in a large, three-bedroom house that Winnie had custom-built for *the* growing family. That is, until the medical costs started piling up, and the house was sold to service the debt. Today, Mercy can barely afford the K Sh 2,500 (US\$25) monthly rent and is reliant on the support of friends.

It all started in 2012, when 73-year-old Winnie began to experience chest pains. Mercy, who worked as a HIV counselor, took her mother to Kilifi Hospital located 60 kilometers away. As that hospital had run out of film, they were forced to travel to Mombasa 70 kilometers away. The chest X-ray showed that Winnie had pneumonia and was prescribed drugs.

After two weeks, the chest pains returned. Upon the advice of a friend, Mercy took her mother to a private hospital for a chest CT scan, which revealed a tumor that almost completely blocked the esophagus. The doctor recommended an immediate biopsy at the Aga Khan Hospital in Mombasa, which confirmed she had cancer. The surgeon recommended immediate surgery, but due to the the doctors' strike, the surgery was postponed. With *dwindling* options, the surgeon recommended conducting the surgery at the least expensive private facility where he had admission rights. Once admitted, the surgeon realized that the tumor had metastasized to the stomach, and an esophageal stent insertion was needed to enable Winnie, now in critical condition, to be able to eat.

Following the surgery, Mercy used a blender to prepare liquid food for her mother, who was now living with her. *"I used to buy six liters of Coca-Cola every week to clean the stent,"* Mercy recalled. *"Then daily trips to KEMRI [Kenya Medical Research Institute] to clean and dress the surgical wound, and monthly trips to Mombasa for checkups with the surgeon."* With debts rapidly mounting, Mercy tried to save money where possible, even learning how to clean and dress the wound to save on daily trips to the hospital. Winnie's condition kept deteriorating. Mercy felt immense pressure from siblings to take her mother to Nairobi for radiotherapy, but there was not enough money, and the doctor advised against it as she was too weak to undergo radiotherapy.

Without any form of health insurance, nearly all medical and nonmedical costs incurred over the course of Winnie's cancer were paid out-of-pocket. Mercy mobilized funds from colleagues, tapped savings, and took out an emergency loan. The experience of the illness, lack of support from family, and loss of a stable job left Mercy in psychological turmoil.

In December 2013, Winnie succumbed to cancer. Mercy was left mourning with a mounting financial debt. *“I used to have nightmares about madeni [debts]. I would wake up sweating and feel so much pain in my heart that the tears would start flowing,”* Mercy said. *“I was not sleeping, I lost my appetite, and I had no peace. People would call me [to ask for their money].”*

As a result of the cancer experience, Mercy founded an NGO called *Mulika Saratani* in 2016. The organization aims to raise awareness of the importance of cancer prevention, screening, and management. Running the organization has helped Mercy cope and enabled her to help others, while many well-wishers have in turn provided emotional support.

## ELIZABETH

It was late in the evening when Elizabeth arrived home after a long day at work. The 38-year-old single mother of two girls, who lives in Timau, manages to keep the family afloat by working as a store clerk at a local horticultural farm. Elizabeth worked at the farm for the past 11 years, starting out doing physical labor and transitioning to less strenuous work after she was diagnosed with cancer.

Elizabeth’s health problems started in 2005, after the traumatic seven-month miscarriage of twins. In 2007, *her uterine* fibroids were removed. However, Elizabeth’s condition worsened. She started to have frequent bouts of cervical pain, interspersed by extended and irregular menstrual periods.

At the hospital, she was told the bleeding would normalize in time, and conceiving would help improve the situation. In 2010, Elizabeth gave birth to a second daughter. Despite multiple reassurances from the doctor, the bleeding persisted. In August 2014, a pap smear led to a diagnosis of *stage II cervical cancer*. Elizabeth was referred to the Kenyatta National Hospital (KNH) in Nairobi for chemotherapy and radiotherapy. Once in Nairobi, Elizabeth was put on KNH’s waiting list with 20,000 other patients waiting for chemotherapy and radiotherapy.

While waiting to hear back from KNH, Elizabeth was referred to a private facility, Texas Cancer Center, where she started treatment immediately and was prescribed eight rounds of chemotherapy and thirty rounds of radiotherapy.

Living expenses (i.e., renting a room, buying fresh produce and medications, and paying for transportation) over the course of three months in Nairobi—a high-cost living area—strained Elizabeth’s marital relationship. *“I spent a lot of money, and at times, I couldn’t bring myself to ask [my husband] for funds when I needed to go to the clinic. When coming back, he was a bit hesitant to come home,”* Elizabeth noted. *“Maybe he saw there was no benefit with living with me.”*

Elizabeth’s younger daughter was also impacted by her mother’s cancer. *“The younger daughter is going to class two. I had her repeat because I couldn’t leave her alone while I went to chemo. I used to travel with her to Nairobi. I had no one to leave her with.”*



Luckily, Elizabeth had a strong social safety net to support her during dire times. Elizabeth's father made the difficult decision to sell a one-acre plot of land in Naivasha to contribute to the rising medical costs, while her brother contributed money for her upkeep. In addition, Elizabeth's employer extended a lifeline through a pooled emergency fund set up for staff as a social scheme, which was able to cover 90 percent of the cost of the chemotherapy and radiotherapy.

*"The help from my employer was the biggest support system I had," she noted.*

*"Since 2015, I have been in remission and on maintenance treatment."*

Several key recurrent themes emerge from the two stories as well as from the focus groups:

- *The cost of cancer diagnosis and treatment can quickly spiral out of control with a high risk of impoverishment.* While this was a common theme across the case studies, Winnie's story epitomizes the gravity of the financial burden for the family of a cancer patient. Diagnostic tests and treatment regimens are costly and can have catastrophic implications on patients and their families. Nonmedical expenses also escalate quickly, and patients need special support to cover living expenses and transportation costs, as many too ill to work lose their livelihoods.
- *Strong social safety nets and family structures can help mitigate the financial burden of a cancer diagnosis.* Families where breadwinners are engaged in formal employment and benefit from employer-provided social welfare schemes are better equipped to cope with the catastrophic spending. Likewise, families with assets (i.e., land, livestock, and houses) are in a position to liquidate them to free up resources for urgently needed diagnostic procedures, costly medications, and expensive treatments in private health facilities if they are unable to access lower-cost public sector facilities. By contrast, families with breadwinners with limited assets who engage in informal work often struggle with mounting debts. Winnie's story shows how her cancer diagnosis devastated the livelihood of the family's main breadwinner—with no health insurance, limited reported employer support, and unreliable financial contributions from the family, Winnie's daughter had to rely on a loan at an exorbitant interest rate to pay for an emergency operation, which resulted in crippling debt and impoverishment, with intergenerational consequences on household finances, mental health, and children's well-being. By contrast, Elizabeth's journey highlighted how a strong family social network and a supportive work environment helped her to deal with and recover from cancer even though the financial burden strained her marriage, put pressure on her father's livelihood, and resulted in her daughter dropping out of school temporarily.
- *The limited NHIF benefit package was another issue that emerged from these personal testimonials as well as from focus groups.* Most patients were not enrolled in the NHIF at the time of their cancer diagnosis. Key informants noted that even when enrolled, the current NHIF basic package does not cover complex drugs outside the Essential Medicines List nor specialist consultation fees, which can exceed the cost of the original diagnosis.<sup>4</sup> Some medications need to be taken for years after the initial treatment, and consequently, patients can incur large out-of-pocket spending. This was true in Elizabeth's case, where monthly injections and costly medicines were prescribed over a period of three years, with the overall cost surpassing the cost of the initial chemotherapy and radiotherapy.

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4. Following the completion of this study, Kenya has updated the Essential Medicines List, which now includes new drugs for breast cancer and leukemia treatment.

- *Lack of counseling after a cancer diagnosis and inadequate understanding of treatment options make it difficult for patients and caregivers to take informed decisions.* Information about palliative care options may not be provided systematically, and difficult discussions around treatment versus palliation do not take place regularly, as doctors tend to focus on curative options. Families under pressure to do whatever is needed for loved ones may cling to false hopes about treatment outcomes and make huge financial sacrifices, such as liquidating assets, with limited results and poor survival prospects. In Winnie’s case, her children—who contributed nothing to the cost of care—continued to urge Mercy to take their mother to Nairobi for chemotherapy instead of continuing with palliative care, even though Winnie was too weak to travel.

## POSTTREATMENT: A MOTHER’S DILEMMA

### JAMES

“*We need to amputate his arm,*” Christine recounted the blasé manner of the doctor who made that statement. “*What mother would let a doctor who may have a conflict of interest amputate a healthy child’s arm?*”

Christine waved in the direction of James, eyebrows furrowed. Nearby, 12-year-old James was full of life, bouncing with excitement at the presence of new visitors in their modest, two-room house in Mwiki. Christine, a 36-year-old single mother of two, had gone through many hardships since the death of her parents, dropping out of high school when there was no money for school fees, marrying and becoming pregnant at the tender age of 21, and separating seven years later.

In late 2017, while showing off his somersaulting skills to friends, James fell unexpectedly after experiencing some weakness in his left arm. The weakness became progressively worse, and James had unexpected falls and fatigue, and was no longer able to lift heavy items. When a soccer game resulted in another fall, he was taken to the Kiambu County Hospital for an X-ray and was prescribed painkillers.

Two months passed, and James’s condition did not improve. Back at the Kiambu County Hospital, the doctor observed that a “*small dot*” seen in the first X-ray had grown. James was referred to a mission hospital in Kijabe, where the doctor prescribed a biopsy at a cost of K Sh 60,000 (US\$600), and the family was asked to raise the necessary funds. Without money or insurance coverage, Christine was only able to raise K Sh 30,000 (\$300) of the necessary amount, and through sheer persistence and tenacity, was able to convince the hospital to conduct the procedure at a discounted rate. Three weeks later the biopsy results were ready.

Rather than providing clarity, the biopsy results added to the confusion as patient files had been mixed up, with one report containing a cancer diagnosis and the other reporting no cancer. Concerned that the cancer diagnosis and recommendation to amputate James’s arm was “*a creation of the hospital,*” Christine took James to Nairobi to seek a second opinion from an oncologist, who *confirmed James’s osteosarcoma diagnosis* and sent him to Kijabe to begin chemotherapy.

With the maturity of Christine’s NHIF membership, James underwent three rounds of

chemotherapy at a private hospital in Kijabe until the funding ran out. After a month-long interruption in treatment, the family went to the Kenyatta National Hospital for the remaining chemotherapy sessions, where amputation was recommended but refused by the family.

*“While it was me who refused the amputation, it was James who said, from the very beginning, he’d better die with his arm,” Christine explained. “He is a big child, and you have to let him speak his opinion. I would have gone through with the amputation, but it would haunt me for the rest of my life.”*

The biggest emotional battle facing the family is the lingering risk of amputation. Given Christine’s precarious financial situation and the possible need to amputate, she joined a support group.

Despite the uncertainties, the family remained hopeful. *“I am organizing a charity soccer tournament in June to raise money for James’s treatment in India,”* she stated with an air of silent determination. *“The amputation is not necessary, as I will raise the US\$20,000 to take James to India for a bone marrow transplant.”*

After all, there is no force more powerful on earth than a mother’s love.

## **ANNE**

Anne isn’t sure when exactly she was born as she lost her parents at a young age. She knows that she was born in Karamona Village in Meru County, and according to her sister it was in 1973. She had her first child at the age of 17. As a single mother of four, Anne’s biggest concern in life has always been trying to scrape together enough money to make basic ends meet. In her struggling shop in Isiolo County, Anne sells secondhand clothing to make a living, and makes regular trips to the Gikomba secondhand clothes market in Nairobi.

For a long time, Anne didn’t know why she felt unwell, but she was clear that the *“details should not be discussed”* with other family members.

In 2013, Anne began suffering immense pain in the lower abdomen along with heavy bleeding. Thinking it was a result of the contraceptive pill she was using, Anne stopped taking the pill and switched to an IUD. The switch did little to stop the heavy bleeding and the persistent abdominal pain. At the recommendation of a friend, Anne traveled to Meru, where a faith-based hospital provides free obstetric and gynecological services as part of its outreach program. The health professionals discovered growths in Anne’s uterus, and after analysis of the biopsy, recommended *“surgery to have the uterus removed.”* A total abdominal hysterectomy was conducted, and when the bleeding continued, a surgery to remove the cervix was done a year later.

Even though Anne did not have any form of health insurance, she managed the financial costs using several strategies. The initial screening was done at a free medical camp. The surgeries were paid for by fundraising from family and friends. The postoperative drug therapies were partially covered from her income. Anne also took out a loan from her

women's group.

At the time of the interview, her children were not aware of Anne's battle with cancer. The only reminder of Anne's illness was a persistent backache that made it difficult for her to bend over and do basic household chores in an otherwise outwardly normal-looking life.

Throughout the cancer journey, Anne was alone in dealing with the cancer diagnosis.

*"My husband left me soon after hearing about my diagnosis, and we have been separated for the last five years,"* Anne noted sadly. *"The hardest part is having no one to talk to about my illness."*

Anne's children were away at boarding school during the hospitalization, and after a long deliberation, she decided not to disclose the diagnosis for fear of negatively impacting them.

Anne's participation in a women's group brought not just emotional support but also financial support, as she was also able to take out a loan to pay for treatment.

Both personal narratives illustrate several recurrent themes from other patients:

- *Cancer diagnoses are associated with fear, isolation, and misconceptions.* Fear is pervasive—fear of losing someone, fear of the inability to finance cancer treatments, fear of dying, and fear of the consequences of cancer on children. For some women, fear of stigma and abandonment prevents them from openly disclosing their cancer diagnosis. Family structures tend to be the most important form of support. Some focus group participants noted that women tend to be more supportive than men when their spouses are diagnosed with cancer. Men's views about cancer include that it is communicable, that the wife with cancer would not be able to engage sexually, and that a husband of a cancer patient should be allowed to pursue relationships with other women. Accusations that James's cancer was "inherited" from Christine's family strained relationships and resulted in the family's refusal to provide support. Similarly, Anne's cancer diagnosis was discovered by her husband through a peer and resulted in abandonment and withdrawal of support.
- *Parents find it especially difficult to cope with childhood cancers and take difficult decisions about treatment.* When a child is diagnosed with cancer, health professionals may face difficulties in discussing the management of the illness with parents. Children are often disempowered to speak for themselves or to make decisions about their own medical care. In Christine's case, the way the doctor communicated James's cancer diagnosis and need for an amputation served to fuel distrust in the medical establishment and to create a misconception that the recommendation to amputate was financially motivated. Christine was tasked with an impossible dilemma as a mother: to agree to amputation, or to refuse it at the risk of the cancer progressing. It was due to James's adamant refusal to undergo the amputation that she did not follow medical advice from two doctors at different hospitals and took on instead the ambitious task of raising funds for bone marrow treatment.

## EPILOGUE: A PATIENT'S ROAD TO RECOVERY

### VICTOR

*"Hi, I'm Victor. I'm a proud bone cancer survivor."* Victor radiated with confidence, and it was easy to miss that the beaming young man who warmly welcomed us into the single-room house in Kariobangi North was missing a leg. The 22-year-old comes from a family of seven siblings.

In 2013, when Victor was a student in the Ruaraka Secondary School in Nairobi, his knee started to swell, and he experienced pain. Thinking it was nothing more than a soccer injury, the family dismissed it.

One morning during a school assembly, Victor collapsed in front of the building. His father was called to the school and asked to take Victor to the nearest private health facility located five kilometers away. An X-ray was taken, and Victor was referred first to the Kiambu County Hospital and subsequently to the Kenyatta National Hospital for a biopsy. Since the family had no health insurance, it took his father three months to mobilize the necessary funds for the biopsy. Almost two months after that, Victor finally had a *biopsy confirming he had osteosarcoma*.

By this point, Victor's knee had swelled to the size of his head and was excruciatingly painful. The doctor at Kenyatta National Hospital recommended amputation. Victor was filled with fear. He was worried about dying on the operation table, of how others would view him with one leg missing, or of dying postoperation as a result of this *"killer disease."* Nonetheless, Victor agreed to go through with the amputation in the hope that it would provide relief from the pain. Due to the long waiting list and his low hemoglobin levels, Victor had to wait four months for the surgery. A week after the amputation, Victor was discharged from the hospital on crutches. After two months of weekly follow-up visits for painkiller injections and wound cleaning and dressing, the stitches were removed, and Victor was advised to seek chemotherapy.

With his father working as a carpenter and his mother selling fish in their Nairobi neighborhood, the cost of 26 rounds of chemotherapy, at K Sh 10,000 (US\$100) each, was beyond their means. A choice was made to completely forgo treatment.

At the time Victor was first referred for a biopsy, his father had lapsed with the payment of the NHIF membership and had to take out a loan for which his land was used as security. By the time the amputation was performed, he had reenrolled the family in the NHIF, so surgery costs were covered. The postoperative costs required liquidating family assets, giving up the family's livelihood, and moving back to the village.

The loss of a leg has changed life forever. Victor misses jogging and playing soccer. Nevertheless, he is optimistic about the future. He is able to earn some income as a cancer advocate. He was also able to catch up on the lost year of school with the help of teachers and classmates and to graduate from high school. Victor hopes to become a teacher and refuses to let the missing leg keep him from working toward his dream. Victor would like to

know if he is really free of cancer. He knows that once he has a job, and stable NHIF membership, he will be able to find out.

*“After all, my mom told me that even if I hide in the house for the rest of my life, my leg will never grow,” Victor noted thoughtfully. “The earlier I come out the better, the sooner people will get used to my condition and feel it is normal. This is what motivated me.... Now, I’m used to it. If a child asks me where my leg is, I tell them it is in the hospital.”*

Some final lessons from this personal story and from the other testimonials and focus group discussions:

- *Patients and families strive to remain resilient throughout the cancer journey, which is riddled with difficulties in accessing services promptly; receiving accurate information; coping with catastrophic spending; and dealing with fear, stigma, and isolation. Victor’s story, like that of others interviewed, highlights the resilience and hopefulness of cancer patients in the face of hardships. They join social support groups and establish civil society organizations to raise awareness and advocate for cancer patients.*
- *The cancer journey can last for years, with patients and families struggling with mounting debts and uncertainties about survival prospects. Victor could not confirm whether his cancer had fully gone away after the amputation. The focus group participants noted that postoperative costs contribute to the financial hardships faced by patients. Wheelchairs, prosthetics, and physiotherapy are not covered by the NHIF and are often unaffordable. The trade-offs and sacrifices parents and caregivers often make when faced with a cancer diagnosis, including leaving jobs to care for a sick relative and selling assets, are part of the continuing struggles faced along a cancer patient’s journey to recovery.*

## **STUDY FINDINGS: ECONOMIC AND SOCIAL IMPACT OF CANCER**

The key messages on the economic and social impact of a cancer diagnosis are as follows:

- *Most patients/households suffered economic losses due to lost wages, sold assets, and, in some cases, growing debts, as well as significant medical and nonmedical spending on cancer care. All households reported loss in income, and three-fourths reported having to sell assets or to borrow to cover the costs of cancer-related care. Virtually all patients were diagnosed at an advanced stage and spent substantial resources, often with poor outcomes. Some patients incurred unnecessary spending stemming from inaccurate diagnoses and multiple tests at different facilities as well as from the use of traditional healers.*
- *None of the eight patients interviewed were enrolled in the NHIF prior to their cancer diagnosis but two-thirds subsequently enrolled and reaped benefits for a limited but costly set of interventions (e.g., chemotherapy, radiotherapy, and surgery). There is a positive likelihood of reduced cancer care cost burden from health insurance enrollment, especially for high-end treatments such as radiotherapies, chemotherapies, and surgeries. However, having health insurance did not always ensure significant financial protection, as other costs (e.g., drugs and diagnostics) can be expensive and have a more limited coverage under the NHIF. Given that there are limited financial protection mechanisms against cancer care costs, households are likely to bear a significant out-of-pocket cost burden from cancer care. Moreover, as there are presently few public facilities offering affordable quality cancer care, patients are either traveling long distances to avail themselves of services or seeking services in the private sector. The nonmedical care costs (e.g., transportation and*

accommodation) are significant, representing one-fifth of cancer-related costs for patients.

- *In summary, cancer care has both substantial medical and nonmedical cost implications as well as losses in productivity and livelihood of patients and their families.* In this study, cancer-related household costs were variable and depended on a range of factors including the type and stage of the cancer diagnosis or treatment, timing and place of care received (or not received), and sources of health care financing. This section summarizes the salient findings on the economic and social impact of cancer from case studies/personal narratives and focus groups.<sup>5</sup> Annex III includes a summary of patient-recalled costs.

**Households are not financially protected against all cancer-related costs.** Many interviewed patients were engaged in informal sector work, reporting their monthly household income to be in a wide range between \$31 (K Sh 3,100) to \$623 (K Sh 62,300) or annual household income of \$375 (K Sh 37,500) to \$7,477 (K Sh 747,700).<sup>6</sup> All patients reported loss in income during their cancer care journey. Several reported having to sell off their assets or borrow to cover their health care costs. For example, one uninsured cancer patient, incurred a debt of almost \$20,000 (K Sh 2 million), compared to an annual household reported income of \$5,400 (K Sh 540,000).<sup>7</sup> In addition, all patients faced an adverse impact on market consumption, reflecting additional spending on transportation, accommodation, and special food; while some faced downsizing in living arrangements or changes in livelihoods. While not easy to quantify, virtually all patients and most family members faced a disruption in economic activity with less time for nonmarket consumption/leisure activities. Several households and key informants noted concerns with the adverse impact on human capital investments, with some children facing disruptions in schooling either due to their illness or that of family members, or the inability of caregivers to cover school costs as funds are prioritized for cancer care. About two-thirds of the interviewees enrolled in the NHIF program. However, all enrolled late after they or family members were diagnosed with cancer, so they may not have fully benefited from reimbursements. Consequently, all households incurred out-of-pocket payments for cancer care.

**Cancer-related costs are likely to be significant for households.** Within this small sample group, the total cancer-related costs ranged between \$946 to \$24,263 (K Sh 94,640 to K Sh 2.4 million) per episode (Table 1a).<sup>8</sup> At least three-quarters of the costs were related to medical expenses. The median spending for cancer-related medical care was \$2,160 (K Sh 215,990), which in most cases was much higher than the household's annual reported income (Table 1b). Even though recalled costs were per cancer episode and not necessarily per year, the order of magnitude of household spending (compared to income) suggests a high risk of impoverishment.

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5. The information in this section should be used cautiously as the study was not an income-expenditure one and did not capture all household income or full consumption; hence, the information is used for illustrative purposes.

6. Several patients reported household incomes that were considerably above the national average (i.e., national per capita income in Kenya is about US\$1,200).

7. No data were collected on household assets, savings, or investments.

8. The total cancer-related costs include both direct medical and nonmedical costs as well as indirect costs (i.e., lost income, averted savings, deferred costs associated with decreased investment in children's education, and nonmarket impacts such as reduced household production and fewer leisure activities).

**Table 1a. Cancer-related Total Medical and Nonmedical Costs  
(K Sh and US\$)**

|               | Cancer-related total costs |               |           |
|---------------|----------------------------|---------------|-----------|
|               | Insured (5)                | Uninsured (3) | All (8*)  |
| Median, K Sh  | 289,320                    | 146,050       | 235,110   |
| Median, US\$  | 2,893                      | 1,461         | 2,351     |
| Average, K Sh | 723,576                    | 262,430       | 550,646   |
| Average, US\$ | 7,236                      | 2,624         | 5,506     |
| Min, K Sh     | 170,300                    | 94,640        | 94,640    |
| Min, US\$     | 1,703                      | 946           | 946       |
| Max, K Sh     | 2,426,260                  | 546,600       | 2,426,260 |
| Max, US\$     | 24,263                     | 5,466         | 24,263    |

\* Total number of patients interviewed for study (n=8)

Source: Study Authors.

Note: Includes all cancer-related costs, including transportation, accommodations, food, interests on medical loans, etc.

**Table 1b. Cancer-related Total Medical Costs  
(K Sh and US\$)**

|               | Cancer-related total medical costs |               |           |
|---------------|------------------------------------|---------------|-----------|
|               | Insured (5)                        | Uninsured (3) | All (8*)  |
| Median, K Sh  | 260,480                            | 128,950       | 215,990   |
| Median, US\$  | 2,605                              | 1,290         | 2,160     |
| Average, K Sh | 569,826                            | 192,917       | 428,485   |
| Average, US\$ | 5,698                              | 1,929         | 4,285     |
| Min, K Sh     | 151,150                            | 93,200        | 93,200    |
| Min, US\$     | 1,512                              | 932           | 932       |
| Max, K Sh     | 1,785,300                          | 356,600       | 1,785,300 |
| Max, US\$     | 17,853                             | 3,566         | 17,853    |

\* Total number of patients interviewed for study (n=8)

Source: Study Authors.

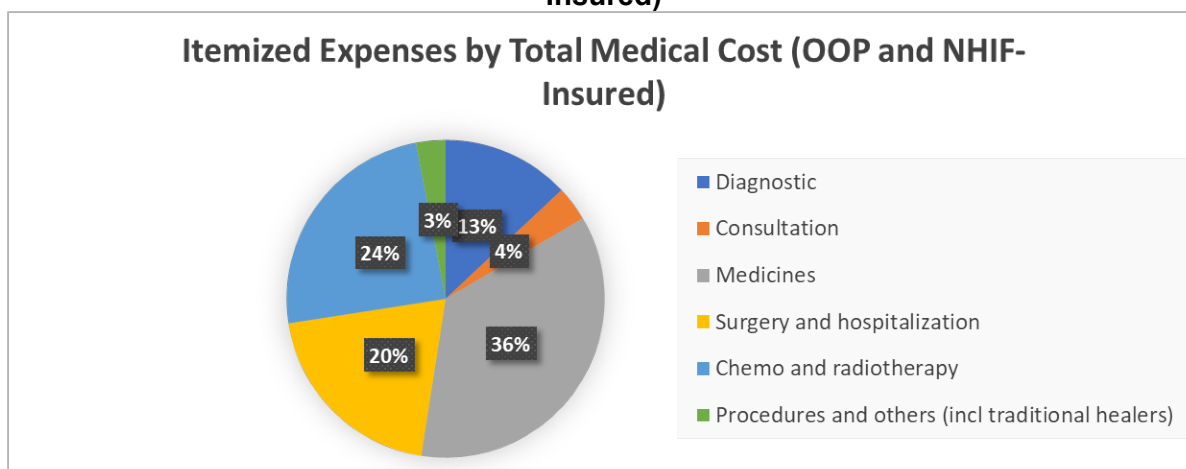
Note: Includes all costs, whether paid out-of-pocket or reimbursed through insurance or grants.

**The highest cancer cost burden is from medicines (36 percent), which have limited coverage under the NHIF, followed by chemotherapy/radiotherapy (24 percent) and surgery/hospitalization (20 percent),** as shown in Figure 3. For example, one insured cancer patient reported spending at least \$10,000 or K Sh 1 million (60 percent of the reported cancer episodic medical cost) on medicines/drugs. Both insured and uninsured patients incurred significant expenses on medicines, averaging approximately \$1,538 or K Sh 153,810 (ranging from K Sh 500 to K Sh 1 million). The itemized medical related costs incurred by respective cancer



patients (Figure 4) varied widely, and depended on how quickly patients were diagnosed, the type of cancer they had, and/or their ability to pay for the required treatment.

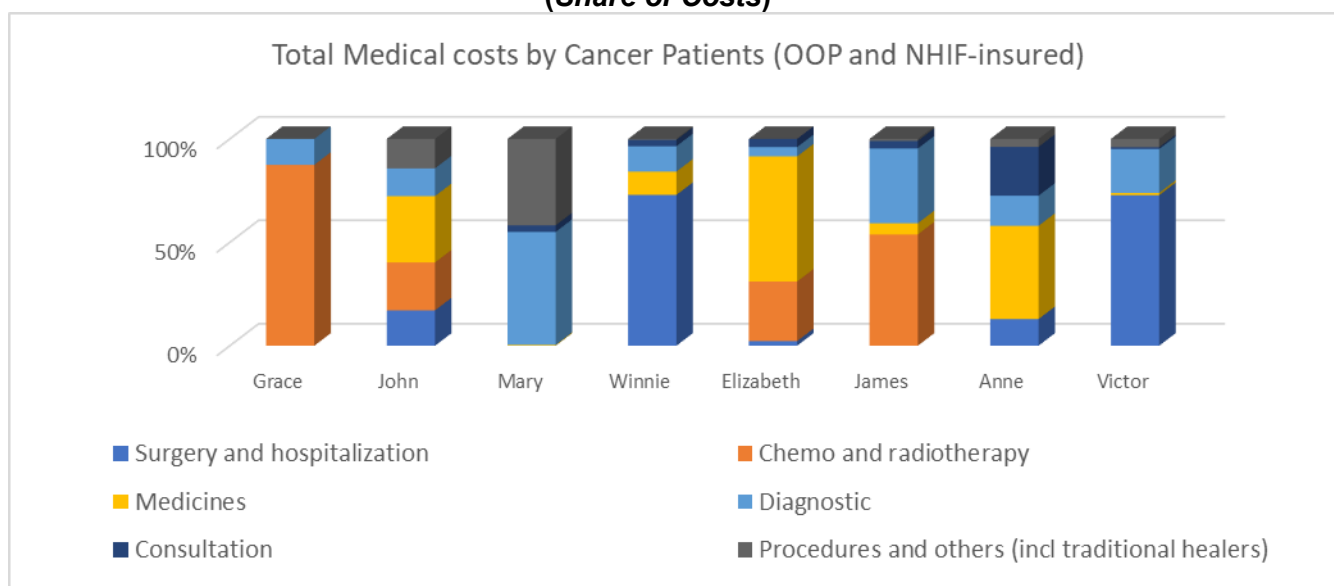
**Figure 3. Share of Total Medical Costs, by Subcategory (OOP and NHIF-Insured)**



Source: Study Authors.

Note: OOP = Out-of-pocket; NHIF = National Hospital Insurance Fund.

**Figure 4. Itemized Medical-related Costs Incurred by Cancer Patients (Share of Costs)**



Source: Study Authors.

Note: OOP = Out-of-pocket.

**The NHIF provides some financial protection, but there is a significant out-of-pocket expense that households continue to bear.** Roughly two-thirds of the cancer patients enrolled after diagnosis in the NHIF, and almost all benefitted through reimbursements on their treatment costs. For example, the cost of surgery (K Sh 350,000; US\$ 3,500) was reported to be fully covered for one NHIF beneficiary, who was able to reduce his OOP costs for cancer treatment by at least 23 percent (from K Sh 151,150 to K Sh 116,150; from US\$1511.50 to US\$1161.50) with this NHIF reimbursement. The cost of chemotherapy was reported to be fully covered for all other NHIF beneficiaries, who reported to have reduced their OOP expenses ranging between 29 percent (K Sh 1,785,300 to K Sh 1,271,300; US\$17,853 to US\$12,713) and 97 percent of their cancer-related medical costs (K Sh 171,500 to K Sh 5,000; US\$1,715 to US\$50). The NHIF program offers reimbursements for its beneficiaries, primarily for cancer treatment (radiotherapy, chemotherapy,

and surgery); whereas other categories such as drugs, diagnostics, and consultations are only partially covered. Likewise, while the NHIF covers cancer treatment costs incurred at both public and private health facilities, the latter is very costly, as private provider fees for households can be higher than reimbursement levels. For example, one household that accessed private care incurred costs that were nearly 11 times higher than for those who used public facilities. In short, despite enrolling in the NHIF, cancer patients still pay a significant share of their medical care cost out-of-pocket. Overall, insured patients were likely to face a lower, or in some cases similar, OOP expense compared to uninsured patients. The variability of costs is higher among the insured compared to uninsured patients, as the former are more likely to seek care earlier; however, some of the care sought may not be reimbursable (Table 2).

**Table 2. Cancer-related Out-of-Pocket Medical Care Costs  
(K Sh and US\$)**

|               | <b>Cancer-related Out-of-Pocket Medical Care Costs</b> |               |           |
|---------------|--|---------------|-----------|
|               | Insured (5)  | Uninsured (3) | All (8*)  |
| Median, K Sh  | 130,700  | 128,950       | 129,825   |
| Median, US\$  | 1,307  | 1,290         | 1,298     |
| Average, K Sh | 335,726  | 192,917       | 282,173   |
| Average, US\$ | 3,357  | 1,929         | 2,822     |
| Min, K Sh     | 5,000  | 93,200        | 5,000     |
| Min, US\$     | 50   | 932           | 50        |
| Max, K Sh     | 1,271,300  | 356,600       | 1,271,300 |
| Max, US\$     | 12,713   | 3,566         | 12,713    |

\*Total number of patients interviewed for study (n=8)  
Source: Study Authors.

**Cancer patients are likely to face considerable out-of-pocket financial burden during their cancer care journey, with those who have access to the NHIF being better off.** Nevertheless, even those who are covered by NHIF still incur substantial OOP spending. Hence, the government’s ongoing efforts to review the NHIF package, to enhance coverage of a broader range of interventions, are critical. The preventive aspects for cancer were not included within this study but are a critical area of concern to educate the population and improve access to diagnostic services at affordable prices.

**Most cancer patients and family members in this small qualitative study reported adverse social and psychological impacts, stemming from stigma, family conflicts, and/or broken marriages.** Focus group participants and several expert informants also emphasized the damage to social relationships that result from the cancer experience, with many broken marriages and destroyed families.<sup>9</sup> Other informants noted that people struggle to interact with cancer patients;

9. As noted by one FGD informant, “By the time the patients die, their relationship is spoilt with everyone. You see there are so many fundraisings in between, there is visitation to hospital; there is visitation at home. Cancer is a hater disease, by the time you die, you don’t have finances; you are very poor; you don’t have friends because amidst the disease, they do not understand you somewhere, and you do not understand them. So, you become so harsh, if you talk to caregivers,

some avoid and/or abandon them, leaving cancer patients lonely and angry at the world and exacerbating the healing and recovery process.

## **FACTORS THAT INFLUENCE A PATIENT'S CANCER JOURNEY**

The study found a range of factors that influence how individuals and their families cope with the diagnosis and treatment of cancer. These include the type of income-generating activity an individual/family members are engaged in, the extent to which they own assets, strength of social relationships and social safety nets, and the gender of the patient. Understanding such factors may provide insights into improving benefit packages and complementary social protection mechanisms. This section summarizes these determining factors.

### **FACTOR 1: FORMAL EMPLOYMENT AND ASSET OWNERSHIP**

Whether patients or close family members are formally employed or have a stable income makes an important difference in dealing with the financial burden of cancer care and treatment. Several participants recounted reliance on siblings with a regular income to help pay for treatment costs or living expenses. Employer-sponsored social welfare schemes made an important difference for some families at times of financial and emotional distress. Case study participants or family members who owned assets were better able to cope with the cost of cancer treatment, but liquidating assets resulted in lost income.

### **FACTOR 2: SOCIAL AND CULTURAL NORMS**

The quality of social networks and family structures proved critical in mitigating the impact of a cancer diagnosis for participants in this small study. Several participants reported strong social and psychological support and solidarity from family members and a broader network of friends and church members, which made a significant difference to their mental well-being. Other cancer patients suffered from fear of stigma, isolation, and loneliness, preferring to keep their condition private, which contributed to strained relationships because of the trauma and stress of the illness and to delayed health-seeking behavior. Both men and women appear to be affected by erroneous beliefs or suspicions that reproductive cancers may be the result of infidelity.

The quality and duration of marital relationships appear to substantially affect how the patients coped and managed. Among the limited number of participants interviewed for this study, elderly patients in long-standing marriages appeared less likely to face separation and abandonment than married women of childbearing age. The distribution of financial responsibility when an elderly parent is sick may be related to the quality of the relationships between the parent and the adult children and among the siblings.

### **FACTOR 3: GENDER OF THE PATIENT AND THE CAREGIVER**

The stories recounted by female cancer patients and survivors suggest that the cultural upbringing of their spouses or partners may play an important role in how they deal with the cancer diagnosis. Several female cancer patients were in a position of economic vulnerability as their spouses or long-term partners did not appear to have a strong social or cultural obligation to support them throughout the illness. Based on the personal narratives and expert accounts, women of childbearing age appeared particularly vulnerable to abandonment by their partners.<sup>10</sup> In addition, women may be more vulnerable to psychological distress, as the two main cancers afflicting women (i.e., cervical and breast cancer) are associated with embarrassment and loss of gender

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*they will tell you sometimes patients get so mad, angry, so they leave them. They die very painfully, those are the consequences."*

10. There might be a cultural notion that if a woman has lost the ability to bear children, the man can look for another wife.

identity. There may also be gender differences in caregiving, with women often spending more time caring for loved ones, even though resources are often controlled by men. This can put women in stressful situations as they face high expectations and have limited control over resources.

#### **FACTOR 4: OPPORTUNITY AND ACCESS TO PROFESSIONAL AND PEER SUPPORT**

Cancer patients or caregivers who received individual support from a health professional or social worker to identify treatment options and ways to mitigate costs reported that the support made a critical difference to how they coped with the cost and the psychological impact of the disease. The importance of cancer support groups and counseling sessions was highlighted by experts and focus group participants alike. Finally, workplace policies that make available emergency loans and social safety net funds can make a difference on cancer's economic, psychological, and social impact on patients.

#### **FACTOR 5: ACCESS TO THE NATIONAL HOSPITAL INSURANCE FUND**

*Many cancer patients struggled with out-of-pocket spending, choosing to either mobilize funds from family and friends or to defer tests/treatment until the conclusion of the NHIF waiting period due to delayed enrollment. NHIF membership is critical to accessing treatment and care. Timely enrollment in the NHIF allows patients to seek care at an earlier, more treatable stage. Some civil society organizations subsidize NHIF membership fees.*

#### **FACTOR 6: DECISIONS MADE IN HOUSEHOLDS AFFECTED BY CANCER**

*All case study participants confirmed that decisions made by families of cancer patients are fraught with emotional distress, uncertainty, and lack of full information. In some cases, especially when choosing between a public or private health care provider, or whether a surgery should be performed, a decision must be made under pressure due to a deteriorating or critical health situation. This included decisions about which providers to use (public vs. private, traditional healers, pharmacies); how to mobilize funds (i.e., fundraising, liquidating assets); and which treatment options to pursue. Children, even when they are mature enough to make decisions for themselves, are often afforded limited autonomy about their own treatment with family members often making decisions on their behalf. Annex IV includes a summary of key decisions and the factors influencing those decisions.*

### **OPPORTUNITIES TO MITIGATE CANCER COST AND CONSEQUENCES**

#### **NHIF BENEFIT PACKAGE AND SOCIAL SAFETY NETS: REDUCING FINANCIAL BARRIERS TO CARE**

The findings of the study support ongoing plans to improve financial protection and reduce out-of-pocket spending, which would lower financial barriers and enhance prospects for early detection and timely diagnosis. More specifically, the patient narratives suggest the importance of the following:

- **Expanding the benefit package progressively to cover a broader range of interventions.** This includes laboratory tests before and during treatment; imaging diagnostics and pathology services, including private sector services where access to services in public facilities is impeded by limited capacity; outpatient consultation fees of oncologists and other medical specialists; palliative care, both as a complement to curative care and for end-of-life support; and individual and family counseling and nutritional advice. In addition, a mechanism to cover part of the costs of home care would reduce the need for hospital admissions and lower health care costs.

- **Further expanding NHIF coverage for informal sector workers who are particularly vulnerable to health shocks.** The national government could offer subsidized premiums to informal sector workers to incentivize enrollment, increase the risk pool, and expand the population receiving financial protection.
- **Identifying strategies for addressing nonmedical costs associated with accessing specialized services at referral facilities.** Transportation costs to the few hospitals providing high-quality specialized cancer care are a significant contributor to out-of-pocket spending. In the short to medium term, while additional cancer centers are established, patients could benefit from transportation vouchers and/or vouchers for low-cost accommodation in proximity to referral facilities. Some of these interventions could be supported through social safety net programs or employer-supported schemes for those in the formal sector.

## HEALTH-SEEKING BEHAVIOR: REDUCING INFORMATION ASYMMETRIES AND IMPROVING QUALITY OF CARE

Feedback from patients and key informants noted that interventions aimed at supporting households to take informed decisions and to access quality care are critical to improving health-seeking behavior. Key strategies include the following:

- **Improving health literacy, reducing stigma, and enhancing uptake of services.** Targeted awareness-raising campaigns are key to improving knowledge of cancer, including the importance of prevention and early detection. Communication campaigns to promote healthy lifestyles (i.e., reducing tobacco and alcohol consumption, increasing physical activity), and to inform at-risk groups about the symptoms and signs of cancer would promote early diagnosis, reduce stigma, and de-taboo myths and misconceptions.
- **Enhancing knowledge of the NHIF benefit package and urging households to enroll early.** As highlighted by the personal stories of these cancer patients, most households enroll in the NHIF only when they need care. Information about the importance of enrolling early should be widely shared through different modalities (e.g., health facilities and workplaces) along with details about the benefit package and copayments. Information materials should include questions and answers to typical concerns, persons/institutions to contact, and grievance mechanisms.
- **Providing supportive counseling to cancer patients and families to address the psychological, social, and behavioral aspects of a patient's journey.** This would include both health facility and community-based counseling provided by frontline workers. Voluntary family conferences are offered by some palliative care providers. At these meetings, family members or friends chosen by the patient are invited to receive information and support to help them take decisions about the patient's care. According to experts interviewed, such sessions can be instrumental in helping patients/caregivers take difficult decisions. To make sessions useful and appealing, the language used should be clear and accessible to patients/caregivers.
- **Improving health provider capacity and communication skills, ensuring that frontline health workers provide accurate information on prevention and risk factors, accurately recognizing signs and symptoms of cancer and promptly referring patients in need of care.** Patient stories confirmed that awareness and knowledge of cancers need to be enhanced at all levels in the health care system, and that appropriate communication of a cancer diagnosis to patients and family members is critical. Strengthening knowledge and the bedside manner in medical education will help health professionals feel more comfortable about communicating difficult news to patients and

families. Clinicians and nurses need to be better trained to refer patients who appear with persisting symptoms on repeat visits.

- **Supporting palliative care practitioners to provide information and decision-making assistance to households facing difficult decisions, especially where there are emotional or ethical considerations.** This may involve well-coordinated messaging about the value of palliation, as well as mainstreaming the notion that palliative care and conservative management of the disease can be the most reasonable approach and in the best interest of the patient. This type of messaging will prevent feelings of guilt for families and enhance trust in the health system.
- **Empowering and encouraging cancer patients, survivors, and families to establish support groups.** The cancer journey can bring different stakeholders together to better cope and manage. As heard through the voices of cancer patients in this small study, support groups can mitigate fears and foster solidarity. Cancer survivors and family members can become articulate and compassionate advocates for families facing similar situations.

#### **PRIMARY HEALTH CARE DELIVERY: STRENGTHENING EARLY DETECTION, SCREENING, AND DIAGNOSIS**

- **Strengthening access to high-quality primary health care services to support early detection and diagnosis of cancers.** As documented through the patient stories, there is an urgent need to expand the capacity of the primary health care system, as many patients bypass this level and end up accessing care at secondary and tertiary facilities, which become congested.
- **Reinforcing the referral system to ensure that patients diagnosed with a cancer are promptly referred to a facility that can provide treatment and care.** Given the multiple needs of cancer patients, a strong referral and counterreferral system should be in place to help patients navigate the health system and receive urgently needed care.

#### **EVIDENCE-BASED APPROACHES: GENERATING MORE INFORMATION**

- **Conducting further research on the cost of care to inform improvements in the benefit package.** This small qualitative study has shown the importance of producing more robust costing information to better understand the costs incurred by patients, as well as the potential impoverishing effects of high OOP spending, and to identify strategies for mitigation of these costs.
- **Carrying out additional research on the gender dimensions of a cancer diagnosis.** Some patient stories highlighted gender-related issues that need to be better understood and addressed, such as stigma and discrimination stemming from reproductive health cancers. Further research in this area would enhance understanding of these issues and identify appropriate remedial actions, such as improving awareness and knowledge and demystifying fallacies and misconceptions.

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## ANNEX I: SUMMARY OF NHIF NATIONAL SCHEME BENEFITS (NOV 2018)

### SUMMARY OF THE NATIONAL SCHEME BENEFITS

|   | Benefit Package           | Eligibility  | Utilization   | Exit  | Cover Limits  |
|---|---------------------------|--|---|---|---|
| 1 | Outpatient Cover          | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> <li>Choice of Outpatient facility</li> </ul> | <ul style="list-style-type: none"> <li>At contracted HCPs</li> <li>Supportive documentation</li> </ul>                            | <ul style="list-style-type: none"> <li>Recovery from illness</li> <li>Defaulting</li> <li>Demise</li> </ul>   | <ul style="list-style-type: none"> <li>Reimbursed through capitation at</li> <li>KES 1,200 for basic care facilities/per year</li> <li>KES 1,400 for tertiary care facilities/per year</li> </ul>                 |
| 2 | Inpatient Cover           | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> </ul>  | <ul style="list-style-type: none"> <li>At contracted HCPs</li> <li>Supportive documentation</li> </ul>                            | <ul style="list-style-type: none"> <li>Recovery</li> <li>Exceeding the limit per family per financial year is 180</li> <li>Defaulting</li> <li>Demise</li> </ul>  | <ul style="list-style-type: none"> <li>Rebate Based payment up to a maximum of KES 4,000 per day</li> <li>Minimum 1,200 per day</li> </ul>  |
| 3 | Maternity Package         | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> </ul>  | <ul style="list-style-type: none"> <li>At contracted HCPs</li> <li>Supportive documentation</li> </ul>                            | <ul style="list-style-type: none"> <li>Delivery</li> <li>Exceeding the limit per family per financial year is 180 days</li> <li>Defaulting</li> <li>Exceeding the age-limit for delivery</li> <li>Demise</li> </ul> | <ul style="list-style-type: none"> <li>Package based to accommodate each case</li> <li>Normal Child Birth at KES 10,000</li> <li>Caesarean Section , KES 30,000</li> <li>Per female beneficiary per FY</li> </ul> |
| 4 | Renal Dialysis Package    | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> </ul>  | <ul style="list-style-type: none"> <li>At contracted HCPs</li> <li>Supportive documentation</li> <li>pre-authorization</li> </ul> | <ul style="list-style-type: none"> <li>Kidney transplant</li> <li>Defaulting</li> <li>Demise</li> </ul>   | <ul style="list-style-type: none"> <li>Renal dialysis offered at a maximum of KES 10,000 per session twice weekly</li> </ul>  |
| 5 | Kidney transplant Package | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared</li> </ul>   | <ul style="list-style-type: none"> <li>At contracted HCPs(where done locally)</li> </ul>  | <ul style="list-style-type: none"> <li>Successful transplant</li> <li>Defaulting</li> </ul>   | <ul style="list-style-type: none"> <li>A package payment of KES 500,000</li> </ul>  |



|   |  |  |  |  |   |
|---|--|--|--|--|---|
|   |  | spouse/beneficiary   | <ul style="list-style-type: none"> <li>Where done abroad, approval through NHIF recognized agent</li> <li>Supportive documentation</li> <li>Pre-authorization</li> </ul> | <ul style="list-style-type: none"> <li>Exceeding the limit per family per financial year is 180</li> <li>Demise</li> </ul>   |   |
| 6 | Radiology Package                                | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> <li>Referral letter</li> </ul> | <ul style="list-style-type: none"> <li>At contracted HCPs</li> <li>Supportive documentation</li> <li>Pre-authorization</li> </ul>  | <ul style="list-style-type: none"> <li>Recovery form illness</li> <li>Defaulting</li> <li>Exceeding the limit per family per financial year</li> <li>Demise</li> </ul> | <ul style="list-style-type: none"> <li>Reimbursed at</li> <li>MRI capped at two per family per year at a maximum of KES 15,000 each</li> <li>CT Scan capped two per family per year at a maximum of KES 8,000 each</li> </ul>   |
| 7 | Oncology Package                                 | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> </ul>                          | <ul style="list-style-type: none"> <li>At contracted HCPs</li> <li>Supportive documentation</li> <li>Pre-authorization</li> </ul>  | <ul style="list-style-type: none"> <li>Recovery</li> <li>Exceeding the limit per family per financial year</li> <li>Defaulting</li> <li>Demise</li> </ul>              | <ul style="list-style-type: none"> <li>Radiotherapy Covered at a maximum of KES 18,000 per week (five sessions) upto a maximum of 20 sessions per family per year</li> <li>Chemotherapy</li> <li>Basic level at KES 25,000 per cycle capped at 6 cycles per family per financial year</li> <li>Complex level at KES 150,000 per cycle capped at 4 cycles per family per financial year</li> </ul> |
| 8 | Rehabilitation: Drug and substance abuse package | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> </ul>                          | <ul style="list-style-type: none"> <li>At contracted HCPs</li> <li>Supportive documentation</li> </ul>   | <ul style="list-style-type: none"> <li>Recovery</li> <li>Exceeding the limit per family per financial year is 180 days</li> <li>Defaulting</li> <li>Demise</li> </ul>  | <ul style="list-style-type: none"> <li>Package rate at KES 60,000 per family per year.</li> </ul>   |

Source: National Health Insurance Fund

|    |   |  |  |  |  |
|----|---|--|--|--|--|
| 9  | Foreign Treatment National Scheme                     | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> </ul>                          | <ul style="list-style-type: none"> <li>Supportive documentation</li> </ul>   | <ul style="list-style-type: none"> <li>Defaulting</li> <li>Exceeding the limit per family per financial year is 180 days</li> <li>Demise</li> </ul>                            | <ul style="list-style-type: none"> <li>Reimbursed at KES 4,000 per day of hospitalization</li> </ul>   |
| 10 | Chronic illness package for Diabetes and hypertension | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> </ul>                          | <ul style="list-style-type: none"> <li>At contracted and designated HCPs</li> <li>Supportive documentation</li> <li>Pre-authorization</li> </ul>   | <ul style="list-style-type: none"> <li>Exceeding the limit per family per financial year is 180 days</li> <li>Defaulting</li> <li>Demise</li> </ul>                            | <ul style="list-style-type: none"> <li>Upto a maximum KES 5,000 per member per year, capitated based on level of treatment needed, initially at GoK county referral and National referral Hospitals</li> </ul>   |
| 11 | Specialized Lab tests Package                         | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> <li>Referral letter</li> </ul> | <ul style="list-style-type: none"> <li>At contracted designated facilities</li> <li>Supportive documentation</li> <li>Pre-authorization</li> </ul> | <ul style="list-style-type: none"> <li>Recovery from illness</li> <li>Defaulting</li> <li>Exceeding the limit per family per financial year</li> <li>Demise</li> </ul>         | <ul style="list-style-type: none"> <li>Up to a maximum of NHIF Board approved rate</li> </ul>  |
| 12 | Surgical Package                                      | <ul style="list-style-type: none"> <li>Fully Paid up member</li> <li>Declared spouse/beneficiary</li> </ul>                          | <ul style="list-style-type: none"> <li>At contracted facilities</li> <li>Supportive documentation</li> <li>Pre-authorization</li> </ul>            | <ul style="list-style-type: none"> <li>Recovery after surgery</li> <li>Defaulting</li> <li>Exceeding the limit per family per financial year is 180</li> <li>Demise</li> </ul> | <ul style="list-style-type: none"> <li>Major Surgeries at a maximum rate of Kshs 80,000 (Level 3&amp;4 HCPs) and Kshs. 130,000 (Level 5&amp;6 HCPs)</li> <li>Minor Surgeries at a maximum of Kshs 30,000 (Level 3&amp;4 HCPs) and Kshs. 40,000 (Level 5&amp;6 HCPs)</li> <li>Specialized surgeries at a maximum of Kshs 500,000</li> </ul> |

## ANNEX II: STUDY DESIGN AND METHODOLOGY

### CONCEPTUAL FRAMEWORK

In the context of the uncertainty and hard choices that cancer patients and their families must face, this study aims to follow the patient's journey through the three areas identified in the conceptual framework (Figure 1) and provide insights into the trade-offs and choices patients make daily. Making informed decisions on the choice of service provider, treatment alternatives, whether to reallocate money from education or savings, mobilizing of personal funds, and palliative versus curative approaches and their corresponding coping strategies are often difficult without complete information. Understanding existing barriers to accessing care will contribute toward broader efforts to improve cancer awareness at the household level and empower health professionals in guiding individuals through these difficult decisions.

**Costs:** Patients face both direct (expenditures incurred for the diagnosis and management of the disease) and indirect costs (lost income, averted savings and investments due to sickness and premature death) associated with cancer. Costs are influenced by choices about service utilization, such as late health-seeking behavior, consideration of different service providers (e.g., public vs. private sector), alternative treatments (e.g., traditional healers), the choice between a curative vs. palliative approach, and postponement or abandonment of treatment. While service utilization in the public sector may have lower patient payments and is generally more comprehensive, there may be longer waiting lists for treatment relative to the private sector.

**Choices and Coping Mechanisms:** Households with a cancer patient face many difficult choices, often in a situation where the patient is grappling with both physical pain and the great uncertainty about the prospect of treatment success. To deal with catastrophic spending, households may either cut down on current consumption or try to maintain it by compensating through liquidation of assets (goods, savings) or by resorting to loans. To cope, patients and their families may decide to cut back on education and investments, sell assets, borrow money, and mobilize contributions from friends and relatives.

**Economic, Social, and Psychological Impacts:** A cancer diagnosis has significant impacts on the economic and social well-being of the patient and the household. Reducing investments in education for children can result in significant longer-term consequences, as the economic cost due to school absenteeism needs to be measured in terms of lower future earnings. These coping mechanisms may result in hard-to-measure deferred costs, as it is nearly impossible for households to assess the long-term consequences of many of these choices and to weigh them against the short-term life or death circumstances. The stigma and fear associated with cancer, as well as compassion fatigue from repeated crowdsourcing of funds from friends and family, may strain relationships. In a Knowledge, Attitude, and Practice (KAP) study published in 2017, cancer patients and caregivers reported they were avoided by members of their social network and sometimes blamed for their treatment decisions and/or perceived to be responsible for getting cancer. The ramifications of cancer on social relationships have impacts on mental well-being, strain existing social security nets, and can also negatively affect employability or eligibility for future support.

## METHODOLOGY

### *Participant Sampling and Recruitment*

At the onset of the study, two exploratory focus group discussions were held with participants recruited with the support of the Kenya Hospices and Palliative Care Association and the Kenyan Network of Cancer Organizations, Nairobi-based organizations that support cancer patients and families across Kenya. The focus group participants represented a range of different backgrounds, geographical settings, and socioeconomic groups (Table A1). Findings from the focus group discussions were then used to refine the selection criteria for in-depth interviews with case study households.

Households with a member who either suffered or suffers from cancer, had survived cancer, or succumbed to a cancer illness were eligible to participate in the study. Eligible households were then identified and recruited with the help of health care providers, cancer support groups, and nongovernmental organizations supporting cancer patients. Households affected by cancer were purposively recruited based on maximum variation sampling to represent a range of cancer types, disease progression stages, socioeconomic status, and NHIF membership. Recruiters informally approached the identified patients and household members to ascertain their interest in participating in the study, inform them verbally about the study objectives and methods, and disclose potential benefits and risks of their participation. Households that agreed to participate in the study were required to sign written consent forms.

| <b>RESEARCH QUESTIONS THAT THE STUDY SOUGHT TO ADDRESS</b>  |
|---|
| <ul style="list-style-type: none"><li>• What is the nature and size of cancer-related costs (direct and indirect) experienced by households, and which costs are perceived to represent the greatest burden?</li><li>• At what point are critical treatment and financing decisions made, about perceived options, and by whom? What motivates the decisions?</li><li>• What life changes do households have to make to adjust to the cancer diagnosis? How have households coped with making these adjustments?</li><li>• How does a cancer experience affect factors such as quality of social life, social capital, human capital, and nonmarket production?</li></ul> |

### *Data Collection, Management, and Analysis*

Data were collected in the form of semistructured, qualitative interviews with patients, survivors, household members, experts, and stakeholders. All interviews were conducted by one of the coinvestigators in Kiswahili or English, on location in the participating households or in other quiet and confidential settings where participants were most comfortable. Prior to the commencement of data collection in the field, all investigators involved in data collection and analysis jointly reviewed and discussed the data collection tools to ensure a common understanding of the questions. The interview data were captured using digital audio recorders. Audio recordings were transcribed by a specialized service that followed strict procedures on data confidentiality. Interviews conducted in Kiswahili were transcribed in Kiswahili and then translated into English. Additionally, retrospective cost information was captured on paper questionnaire forms and transferred to Microsoft Excel. Interview transcripts were imported into the NVivo, a computer-assisted qualitative data analysis software, and used to store, code comment, and organize the data to answer research questions.

## Characteristics of Focus Group Participants

**Table A1: BASELINE CHARACTERISTICS OF FOCUS GROUP DISCUSSANTS**

| <b>VARIABLES</b>                                      | <b>NAKURU, N = 7<br/>(%)</b> | <b>KISUMU, N<br/>= 9 (%)</b> |
|---|------------------------------|------------------------------|
| <b>Gender</b>   |                              |                              |
| Male  | 0                            | 3                            |
| Female  | 7                            | 6                            |
| <b>Mean age (years)</b>                               | 38 (range: 29–51)            | 59 (range: 28–72)            |
| <b>Employment status</b>                              |                              |                              |
| Employed  | 5                            | 7                            |
| Unemployed  | 2                            | 2                            |
| <b>Received support from NGOs/<br/>support groups</b> |                              |                              |
| Yes   | 4                            | 2                            |
| No  | 3                            | 7                            |
| <b>Type of cancer</b>                                 |                              |                              |
| Breast  | 2                            | 2                            |
| Eye   | 1                            | 0                            |
| Hodgkin's lymphoma                                    | 1                            | 0                            |
| Kaposi sarcoma  | 0                            | 1                            |
| Cervical  | 1                            | 2                            |
| Skin  | 1                            | 0                            |
| Oral  | 1                            | 1                            |
| Colon   | 0                            | 3                            |
| <b>Stage of cancer diagnosis</b>                      |                              |                              |
| I   | 2                            | 1                            |
| II  | 4                            | 2                            |
| III   | 1                            | 2                            |
| IV  | 0                            | 2                            |
| Unknown   | 0                            | 2                            |
| <b>Household setting</b>                              |                              |                              |
| Rural   | 3                            | 8                            |
| Urban   | 4                            | 1                            |
| <b>Insured by NHIF</b>                                |                              |                              |
| Yes   | 5                            | 8                            |
| No  | 2                            | 1                            |
| <b>Mean monthly income (K Sh)</b>                     | 4,429 (range: 0–15,000)      | 2,077 (range: 0–8,000)       |
| <b>Treatment status</b>                               |                              |                              |
| Ongoing   | 3                            | 9                            |

|                                     |                  |                   |
|-------------------------------------|------------------|-------------------|
| Completed                           | 4                | 0                 |
| <b>Marital status</b>               |                  |                   |
| Single                              | 3                | 2                 |
| Married                             | 1                | 4                 |
| Separated                           | 1                | 0                 |
| Widowed                             | 2                | 3                 |
| <b>Mean number of children</b>      | 1.7 (range: 0–3) | 3.0 (range: 0–6)  |
| <b>Mean household members</b>       | 4.1 (range: 3–6) | 6.0 (range: 3–11) |
| <b>Type of health facility used</b> |                  |                   |
| Public facility                     | 4                | 9                 |
| Private facility                    | 3                | 0                 |

---

*Source:* Study Authors.

*Note:* NGO = Nongovernmental organization; NHIF = National Hospital Insurance Fund.

## ANNEX III: DIRECT MEDICAL AND NONMEDICAL COSTS OF THE CANCER EPISODE, AS RECALLED BY STUDY PARTICIPANTS

|                  | Direct Direct Medical Costs   | Direct Nonmedical costs   |
|------------------|---|---|
| <b>Grace</b>     | <b>US\$49:</b> Grace paid for an ultrasound and consultation (K Sh 2,000 [US\$20]), two CT scans (K Sh 1,650 [\$16]) and two hemograms for K Sh 1,350 (\$13). The cost of pain medications at a local pharmacy (K Sh 200 [US\$2])/daily was beyond the family's means. A diagnostic CT scan (K Sh 16,500 [US\$160]) was covered by AMPATH through its Breast and Cervical Cancer Programme.   | <b>US\$94:</b> The nonmedical costs involved several trips from Kitale to Eldoret adding up to K Sh 8,000 (US\$80), and shorter trips to Kitale. AMPATH reimbursed transport expenses (K Sh 1,400 [\$14]).  |
| <b>John</b>      | <b>\$1,010:</b> Substantial costs arose before John received the diagnosis. These included a biopsy and tests at a private hospital (K Sh 11,000 [\$110]) and an X-ray at a public hospital (K Sh 8,000 [\$80]). The surgery for the biopsy cost ca. K Sh 25,000 (\$250). John paid high fees to a traditional healer (K Sh 19,000, [\$190] for consultations, and K Sh 3,000 [\$30] for medicines). Total cost for painkillers and maintenance drugs were estimated at K Sh 35,000 (\$350). Going forward, John was expecting monthly medication costs of K Sh 3,500 (\$35/month) for several years. Cost of chemotherapy was covered by NHIF. | <b>\$195:</b> The highest expenditure was related to the cost of food, local transport, and accommodation to a <i>caregiver</i> , who accompanied John during his surgery and hospitalization in Kisumu, an amount of about K Sh 500 (\$5) per day adding up to an estimated total of K Sh 15,000 (\$150) over the course of a month. The remaining K Sh 4,000 (\$40) was for transport costs, which were manageable. |
| <b>Mary</b>      | <b>\$1,250:</b> The medical costs consisted mainly of multiple diagnostic procedures estimated at K Sh 71,000 (\$710) (including several X-rays and scans) as well as costly consultations with traditional healers (ca. K Sh 54,000 [\$540]). Most of the costs were incurred <i>before</i> an accurate cancer diagnosis was obtained.   | <b>\$72:</b> The cost of transport to purchase painkillers and other remedies accounted for about a third of the nonmedical costs (K Sh 400 [\$4] per trip for the duration of 1.5 years before the diagnosis). The remaining costs were incurred for trips to Mombasa and Likoni for diagnoses and consultations. Financial barriers hindered Mary's ability to travel to Nairobi for treatment.                     |
| <b>Winnie</b>    | <b>\$3,420:</b> The direct medical costs paid out-of-pocket included diagnostic procedures, such as a CT scan (K Sh 18,000 [\$180]) and a biospy (K Sh 25,000 [\$250]); an operation at a private hospital (K Sh 260,000 [\$2,600]); drugs (K Sh 24,000 [\$240]); morphine (K Sh 15,000 [\$150]); and postoperative consultation fees.  | <b>\$400:</b> Nonmedical costs included taxi trips between Kilifi and Mombasa, estimated at a total of K Sh 32,000 (\$320); special food that cost about K Sh 8,000 (\$80); and purchase of various equipment (e.g., food blender, wound repair supplies).  |
| <b>Elizabeth</b> | <b>\$15,940:</b> Spending included radiotherapy (K Sh 210,000, [\$2,100] for 30 sessions) and chemotherapy (K Sh 304,000 [\$3,040] for 8 sessions) in a private cancer center (before NHIF coverage became active);   | <b>\$120:</b> Estimated interest on bank loan (K Sh 12,000).  |

and posttreatment monthly maintenance drugs and injections, totaling K Sh 1,080,000 (\$10,800) over a period of three years.

|               |   |  |
|---------------|---|--|
| <b>James</b>  | <b>\$2,400:</b> Diagnostic tests added up to nearly K Sh 95,000 (\$950). These costs included hospital admission for a biopsy and a major surgery performed at a faith-based facility (K Sh 64,000 [\$640]); laboratory tests and imaging (K Sh 22,000 [\$220]); and chemotherapy with copayments for two sessions at a faith-based hospital (K Sh 35,000 [\$350]) with remaining sessions fully covered by NHIF. Other costs included consultation fees (K Sh 10,000 [\$100]) and a range of preoperative and postoperative medicines (K Sh 14,000 [\$140]).                 | <b>\$290:</b> Transportation costs for James and his caregivers came to a total of ca. K Sh 29,000 (\$290).  |
| <b>Anne</b>   | <b>\$640:</b> The largest costs incurred were for posttreatment maintenance drugs estimated at K Sh 42,000 (\$420). The cost for two surgeries in a public hospital (partial hysterectomy and removal of the cervix) added up to K Sh 12,000 (\$120), and five specialist consultancies at the same place to K Sh 5,000 (\$50). The cervical cancer diagnosis was K Sh 5,000 (\$50) at a faith-based hospital. Even though Anne did not have health insurance, fundraising from family and friends allowed her to cover these costs.  | <b>\$12:</b> The nonmedical costs included only public transport (K Sh 60 [\$6] per trip), as Anne did not require further treatment following the surgeries.  |
| <b>Victor</b> | <b>\$4,740:</b> The largest costs to Victor and his family were the direct medical expenses for the biopsy and hospitalization at the Kenyatta National Hospital (K Sh 100,000 [\$1,000]). By the time the amputation was performed, the cost of K Sh 350,000 (\$3,500) was fully covered through the NHIF. However, at that time (2014), NHIF did not have a comprehensive package for cancer, so postoperative costs were paid by the family, including several crutches (K Sh 15,000 [\$150]) painkiller drugs (K Sh 5,000 [\$50]), and consultations (K Sh 4,000 [\$40]). | The nonmedical costs could not be sufficiently quantified retrospectively. They consisted of transport expenditures for multiple trips by public transport to Kenyatta National Hospital for Victor, as well as trips for his parents and siblings to visit him. |

Source: Study Authors.

Note: AMPATH = Academic Model Providing Access to Healthcare; NHIF = National Hospital Insurance Fund.

### Indirect costs experienced by the households in the study sample

| <b>Indirect costs</b> |   |
|-----------------------|---|
| <b>Grace</b>          | Grace had to liquidate possessions and small livestock and lost her livelihood. The inability to work for over one year represented the most serious financial burden and was mitigated through family remittances to cover the cost of food and rent.  |
| <b>John</b>           | John's family lost the income of the main breadwinner. His cessation of work resulted in almost a year of lost income at the time of the interview. The amount lost in the past and future is hard to quantify; as a contractor his income was irregular. In John's own words, he " <i>could get between K Sh 10,000 (\$100) and 50,000 (\$500) per contract.</i> " John became |



|                  |  |
|------------------|--|
|                  | dependent on his wife for simple tasks.  |
| <b>Mary</b>      | Mary had to stop working as a small trader. Based on her estimate of daily income, this may have led to lost income of about K Sh 40,000 (\$388) between the time she stopped working until her death. Her daughter stopped working as a small trader to provide care, and lost an estimated income of K Sh 3,000 (\$30) per month for the duration of the illness. Her husband incurred financial losses, as he could not restock the shop due to liquidity problems and therefore made less sales.   |
| <b>Winnie</b>    | Mercy, Winnie's daughter, lost her livelihood and incurred debts with interest alone estimated at K Sh 150,000 (\$1,500). Mercy says she currently owes about K Sh 2 million (\$20,000) to financial institutions. Her difficulties pushed her to resign from a stable position and lose her monthly salary (K Sh 45,000 [\$450]). Mercy also had a farm business that generated "good money." Due to her mother's illness, the business was neglected with forgone family income.   |
| <b>Elizabeth</b> | Elizabeth had to take unpaid leave due to the illness, leading to an estimated annual salary loss of K Sh 120,000 (\$1,200). Other key indirect costs were her father's loss of a critical asset; and the one-year absence from school for her youngest daughter, who accompanied her to Nairobi for treatment. The medical costs were partly covered through a bank loan (K Sh 500,000 [\$5,000]), and a social welfare scheme (K Sh 460,000 [\$4,600]) on the horticulture farm. The land sale resulted in a loss of potential future income and return on investment, as well as forgone inheritances.  |
| <b>James</b>     | James's mother had to stop working at the Nairobi Water and Sewerage company, which led to an estimated loss of income of about K Sh 10,000 per month for 18 months at the time of the interview (K Sh 180,000 [\$1,800]), placing a heavy financial burden on the family's well-being, as she faced difficulties paying school fees for another child and no longer has a predictable source of income.   |
| <b>Anne</b>      | Due to her illness and backaches, Anne could no longer work on the farm, which in turn has hindered her ability to pay back a K Sh 40,000 (\$400) business loan taken from her women's group.  |
| <b>Victor</b>    | Victor's father had to sell his welding machine, give up the welding business in Nairobi, and move back to the rural village in Siaya County. He also had to sell part of the land in Siaya to be able to repay the loan, resulting in a potential loss of income and loss of inheritance for the children. Victor's mother had to close the fish business in Nairobi to take care of him, leading to a loss of income. Victor missed school for one year, but thanks to the support of his teacher and classmates and his home studies, he was able to join the same class that he left and graduate from high school. The amputation limits the kind of work that Victor can do, resulting in an economic cost that cannot be easily quantified. |

Source: Study Authors.

## ANNEX IV: DECISIONS EMERGING FROM THE CASE STUDIES, THEIR CONTEXT, AND POSSIBLE DRIVERS OF CHOICE

| Decision area   | Decisions   | Drivers or determinants/situational comments   |
|-----------------|---|--|
| Communication   | Disclosure of the cancer diagnosis to family members, friends   | The nature of existing social relationships, the personality and upbringing of the patient, and past experiences may all influence this decision.  |
|                 | In cases of elderly patients (the decision about disclosure of the diagnosis <i>to the patient</i> by relatives)  | Children or other relatives of elderly cancer patients who want to protect the patient from the (perceived) emotional distress of knowing about a cancer diagnosis.  |
|                 | Whether—and how—to ask spouse, relatives, or friends for financial support, especially when it is needed repeatedly   | Being perceived as a burden by others adds to the emotional distress experienced by cancer patients; furthermore, some female patients may fear an increasing risk of being abandoned by their spouse if they ask for financial help repeatedly.   |
| Health provider | Choice of private provider (when there is an option)  | This decision appears to be driven by recommendations and referrals, and the patient's ability to pay for services in the private sector. It is rarely based on an individual's assessment of available options.   |
|                 | Public vs. private sector provider  | This decision is influenced strongly by trust in the provider and by past negative experiences, for instance, when repeated incorrect diagnoses have been received in the public sector. Waiting times for treatment also influence these decisions. In situations when there is an excessive waiting period in the public sector, the decision to go to a private facility can mean the difference between life and death.  |
| Treatment       | Should surgery be undertaken or not?  | Surgeries are associated with fear, both because of the (perceived) possibility of the operation contributing to the spread of cancer, or because of the fear of the consequences of losing an important organ such as a sexual organ or a limb. As a result, patients may decide against surgery.   |
|                 | Should treatment continue even when the prognosis is poor? (E.g., through a second opinion in private sector or travel to India), or should a primarily palliative care-focused approach be chosen? | Such decisions are closely related to the following: <ul style="list-style-type: none"> <li>• The degree of trust in the quality of treatment and diagnosis, based on the experience throughout the patient journey.</li> <li>• The amount of hope for a positive outcome, based on communications with health workers, social interactions, and individual disposition.</li> <li>• Fear of guilt—family members want to be perceived as having done everything possible to save the life of a patient.</li> </ul> |

Source: Study Authors.



The burden of noncommunicable diseases in Kenya is rising rapidly, and now accounts for more than 50 percent of all hospital admissions, and nearly 30 percent of total deaths. Cancer is the second-leading cause of NCD mortality in Kenya, with its incidence nearly doubling between 2008 and 2012. In 2015/16, the National Hospital Insurance Fund introduced cancer care as part of the outpatient benefit package and announced further expansion with a comprehensive cancer care plan based on new protocols developed by the National Cancer Control Programme.

Using a case study approach with focus group discussions and in-depth interviews to shed light on the patient journey, and better understand the direct and indirect costs families face; the difficult decisions and choices they need to make; and the socioeconomic and psychological implications of having a family member afflicted by cancer. The report follows the lives of cancer patients and highlights experiences and lessons from their respective battles along the cancer journey. Some major themes that emerged through the personal narratives include (i) lack of awareness and poor knowledge of cancer and late health-seeking behavior; (ii) difficulties in navigating the health care system and delays in getting an accurate and timely diagnosis; (iii) inadequate health insurance coverage and gaps in the benefit package, which limit access to critical diagnostic tests, treatments, and drugs; and (iv) sociocultural barriers, including stigma, fear, and myths that impede patients from seeking care early. Other themes that emerged relate to the (i) potential impact of social safety nets to mitigate the impact on patients and households; (ii) importance of cancer survivor groups to provide support; and (iii) resilience of cancer patients as they embark on the road to recovery.

This report focuses on factors that influence a patient's journey and proposes a series of recommendations to mitigate the cost of cancer to patients and families.

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