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Community perspectives and insights into cancer surveillance, prevention, and research: an engaged participatory approach to cancer epidemiology research in remote areas of Northeastern Uganda

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Abstract

Background There is limited research on cancer screening, prevention and treatment in the remote areas of Northeastern Uganda. Specifically, there is limited research presenting cancer control stakeholder perspectives in remote settings, whereas stakeholders' perspectives are critical for an engaged participatory approach to cancer control. This study therefore aimed to establish the community (patients, caretakers, opinion leaders, health managers and policy makers) perspectives on cancer surveillance, prevention, treatment and identify priorities for cancer research in Northeastern Uganda.

Methods This qualitative research was part of a stakeholder's consultation on cancer research priorities in Northeastern Uganda for Wellcome Trust research grant application, conducted by a consortium of research partners. Six semi-structured Key Informant Interviews (KIIs), two focus group discussions (FGDs) and one community dialogue meeting were conducted between July and August 2025. Thematic data analysis was conducted to identify emergent themes from the interviews. Findings are presented using the key emergent themes, supporting quotes, and are presented in tables and text. This study is reported in accordance with Consolidated Criteria for Reporting Qualitative Research (COREQ).

Key Findings There was delayed diagnosis in most cases for cancer patients. After the cancer diagnosis, patients were referred to Mulago Hospital, approximately 300Km away from their homes for further treatment, with many hesitations and incapacity to go to Mulago due to many social and economic challenges. There is no stand-alone cancer surveillance system in the country and currently it depends on health facility data which have lots of weaknesses including incompleteness and inaccuracy. Health facilities are ill-prepared to respond to the growing burden of cancers. Priorities for cancer research include epidemiology and etiology of cancer and a focus on population-based registry for unique populations in Uganda and strengthening cancer surveillance systems.

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Conclusion This study highlights the importance of an engaged approach based on Participatory Action Research theory to identify problems. Through this approach, the research team was able to accurately understand the research context, identify research issues, and priorities. Priorities for cancer research identified by this study include epidemiology and etiology of cancer, including the incidence studies and geographical mapping of these cancers, conducting cancer disease surveillance at the landing site and investigating the contribution of the locally available foods and environment to cancers.

There is need for community sensitization and screening for cancers in the entire region. Involvement of community team leaders such as village health teams (VHTs), local council I (LCIs), traditional and church leaders in cancer surveillance should be encouraged and the community case definitions of common cancers should be refined and the capacity of the community workers (VHTs) built to detect cancers at community level.

Through this preliminary research, the groundwork for science anchored on the realities of the affected people has been firmly laid upon which science can build on to solve the problem in a sustainable and equitable way.

Keywords Cancer, Surveillance, Delayed cancer diagnosis, Focused group discussion, Community perspectives, Qualitative research

Introduction

Cancer is still a global challenge with about 20 million cases and 9.7 million deaths in 2022 alone, with more deaths occurring in low- and middle-income countries [1–4]. The most common cancers reported globally are Lung (12.4%), female breast (11.6%), colorectum (9.6%) and prostate (7.3%), with the highest incidence reported in Asia (49%), Europe (22%) and Americas (21%) [1]. The cancer burden in Sub-Saharan Africa (SSA) has been significantly increasing in recent years, with a higher increase in mortality than the rest of the world [4]. SSA is projected to have a greater than 85% increase in the cancer burden by 2030 [5].

Interventions to control cancer in SSA in the past few years have had limited success because of low awareness of the cancer burden and a poor understanding of the potential for cancer prevention due to limited research [5]. Health providers have identified insufficient training support, lack of knowledge on cancer screening techniques and policies as barriers to cancer screening in South Africa [6]. In addition, there is insufficient data for cancer registration, insufficient numbers of skilled health-care personnel, and scarce local, effective, and sustainable research [5]. Cancer research disparities in Africa are attributed to numerous challenges in the research ecosystem ranging from funding, conduct and dissemination of research [7].

Success in cancer research and prevention requires both local and global collaboration from governments, policy makers, funding agencies, health care organizations and leaders, researchers and the public [8]. The barriers to successful cancer prevention and treatment in SSA, have been identified by stakeholders as limited screening, diagnostic facilities and specialists, while lack of universal health coverage policies, limited community-based cancer awareness programs, and lack of national cancer registries were cited as policy and economics challenges which are considered as research priorities [9].

Uganda has been showing an annual increase in cancer mortality from 17,000 to 24,600 in a space of 4 years [10], with significant regional inequalities in cancer diagnosis and treatment, with only one specialized cancer treatment facility located in Kampala. In northeastern Uganda, there is a capacity gap in cancer diagnosis, management, surveillance and research.

Studies done in Northeastern Uganda indicate low cancer screening rates, even among high-risk groups such as female sex workers, screening is still low at 33% [11] and among rural women in Kaberamaido it is at 20% [12], whereas cancer screening is a preferred approach proposed by WHO for early detection and treatment [13].

There is limited research on cancer screening, prevention and treatment in the remote areas of Northeastern Uganda. The few studies done indicate the need to conduct higher level evidence studies to understand cancer epidemiology and progression in such remote areas [14, 15]. The limited studies in the region could be attributed to the remoteness of the region, especially Karamoja, which is vast, with a sparse and nomadic population who are quite hard to reach. In addition, until less than 10 years ago, the region did not have an academic and research institution until the establishment of Soroti University.

It is important to understand the community perspectives and insights into cancer surveillance, prevention and research in this remote area to design a participatory research approach which addresses the local needs and allow for faster uptake and implementation of research findings. This study therefore aimed to establish the perspectives of health workers and policy makers on cancer surveillance, prevention, treatment and identify priorities for cancer research in Northeastern Uganda.

This study applied a theoretical triangulation to have a holistic lens of community perspectives and insight into cancer surveillance, prevention and treatment in the region. The main framework which guided the study was Socio-Ecological Model (SEM) [16–18] which is useful in

analyzing the multi-layered nature of cancer determinants. The study was supported by Eco-Social Theory [19] which focuses on the interplay between the biological, ecological, and social factors, and the Health Belief Model [20] which helped uncover unique issues around risk perception, barriers, and benefits underpinning cancer behaviors.

Materials and methods

Study design

This qualitative study was part of a stakeholder's consultation on cancer research priorities in Northeastern Uganda, conducted jointly by a research consortium including University of Sunderland, University of St Andrews, Makerere University, Uganda Cancer Institute (UCI), and Soroti University. Six (6) semi-structured key informant interviews (KIIs), two (2) focus group discussions (FGDs), one in Soroti University comprised of 4 newly diagnosed cancer patients and 2 care takers (that is, 6 participants in total) and the second one in Uganda Cancer Institute (UCI) comprised of 4 cancer patients from Northeastern Uganda who were receiving care at UCI, together with 2 caretakers (total 6) were conducted. In addition, one dialogue meeting comprising of 15 community opinion leaders were conducted between July and August 2025 to elicit the perspectives of community members, health facility managers and policy makers on cancer surveillance, prevention, treatment and identify priority research areas in the remote areas of Northeastern Uganda.

Study area

The study was conducted in Uganda among the key informants who were purposively selected from Uganda Ministry of Health (MoH), Uganda Cancer Institute (UCI), District health officers (2) of selected districts in the Northeastern region and two health facility in charges of the largest referral facilities in the region. The FGD participants were patients and caretakers of patients who were diagnosed with cancer and either receiving treatment or preparing to travel for treatment. The participants of the dialogue meeting were opinion leaders such as the village health teams (VHTs), religious leaders or local council leaders.

Northeastern Uganda has a population of about 4 million people (2.5 million in Teso and 1.5 million in Karamoja) [21] with three main referral hospitals, and 10 district hospitals (3 in Karamoja and 7 in Teso), with several Health centers IVs and IIIs serving this population. The center of Teso, Soroti City is located about 310Km Northeast of Uganda's capital-Kampala, where cancer patients are referred for treatment, while Moroto which is the center of Karamoja is located 180Km far east of Soroti City (Fig. 1).

The main economic activity in this region is agriculture, where Northern Karamoja is purely pastoral while

Southern Karamoja is agro-pastoral, like Teso. In addition to agriculture, there are some mining activities in Karamoja, with trade and businesses concentrated in the trading centers and Soroti City.

Participant sampling and recruitment

Six key informants were purposively selected to participate in these consultative interviews based on their work and/or policy experience. The two key informants from UCI and Ministry of Health (MoH) were individuals with diverse knowledge and experience in cancer prevention and control policy formulation at national level and were specifically selected to discuss the strategic plans at national level for the cancer prevention and control for the remote areas of Northeastern Uganda, while the two district health officers (DHOs) and the 2 Health facility managers were selected to share the current situation, challenges and propose priorities in the cancer research in the region. The participants included were individuals who had worked in their position for at least one year and who have been actively involved in cancer patient care, referral or policy formulation and dissemination.

The participants included in the FGD were purposively selected based on cancer diagnosis from Soroti University pathology laboratory, since it's the only laboratory in the region currently conducting cancer diagnosis. The patients with confirmed cancer diagnosis were invited together with their caretakers to participate in the FGD at Soroti University or UCI, depending on their location at the time of the invitation. Also, the participants for the dialogue meeting were purposively selected to provide community perspective on cancer diagnosis and management. The participants were identified by the study team, reached through phone calls or emails and invited to participate in the study, after which physical face-to-face and/or online appointments for interviews were made. The researchers reflexively discussed key themes at the conclusion of each interview and the decision to cease recruitment was based on saturation principle and team consensus.

Data collection

The study team developed an interview guide through brainstorming exercise, with predetermined interview questions to help identify participants' perspectives into cancer management and research priorities (supplementary file- S1). The study tools were then piloted within Soroti City and one of the district hospitals, refined before use for data collection. In person and hybrid interviews were conducted, in that some study teams (PI or AM) were connected on zoom while others (RO, HA, LOO, EO or JA) were physically present during the conduct of the interviews. The KIIs were conducted in English, at the participant's place of employment (office), by

Map Showing North Eastern Region and UCI in Kampala

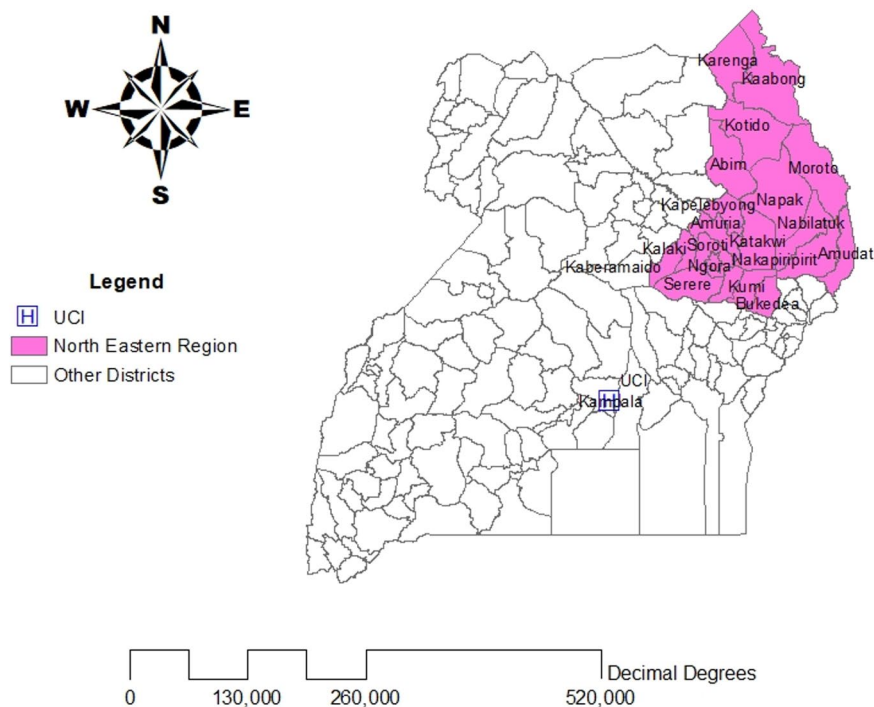


Fig. 1 Map of Uganda showing the location of Northeastern Uganda and UCI

at least two research teams (RO, JA, EO, LO, HA, PI or AM), while the FGDs and Dialogue meetings were conducted in a local language, *Ateso*, and translated into English by the research teams who are fluent in Ateso and English (HA, PI and LOO). Probing questions were used to elicit more detailed information from the key informants, FGDs and dialogue meetings at the discretion of the researchers and kept on evolving based on emergent themes from previous interviews. KIIs took between 30 and 45 min while the FGDs and Dialogue meeting took between 60 and 90 min and were zoom-audio recorded after seeking permission from the participants. Participants were compensated for their time in terms of air-time worth Uganda Shillings 20,000 (~\$6 USD).

Data analysis

Thematic data analysis was conducted to identify emergent themes from the interviews in line with interpretivist / constructivist paradigms [22, 23]. The zoom recordings were transcribed, and four researchers (RO, HA, PI, LOO and JA) jointly listened to the recordings while revising the transcriptions. Additionally, transcript

validation was done by comparing written text against audio recordings through listening to the recordings while reading the written text (transcripts) to confirm findings, check inconsistencies, and annotating non-verbal cues.

Hybrid coding (that is, inductive and deductive coding) to create meanings around the texts and records were conducted. The coding disagreements were resolved through consensus at the end of every coding session. The capabilities (C), opportunities (O), motivation (M) model for Behavior change I (COM-B) [24] was used as a framework during analysis to understand the health workers perspectives and insights into care prevention, treatment and research. Findings are presented using the key emergent themes, supporting quotes, and are presented in text. This study is reported in accordance with Consolidated Criteria for Reporting Qualitative Research (COREQ) [25].

Key findings

The emerging themes, sub-themes and illustrative quotes are summarized in Table 1 below.

Table 1 Themes and sub-themes (Categories)

Theme	Sub-theme (Category)	Illustrative Quotes
1. Perceived causes and risk factors of cancers in the region	1.1: Understanding and misconceptions about cancer	“When I hear about cancer, I know it kills people. I have buried so many people who have died of cancer, resulting from consuming cigarette and alcohol.” (PA01). “They say it’s a virus; we really don’t know if it’s a virus or a worm, so this needs to be clear. Others say its witchcraft” (PA05).
	1.2: Common cancers in the region	“Because of the diagnostic challenges, the cases may not be very many, but the common cancers are Cancer of Cervix, breast and prostate” (KI02). “Another cancer that I hear is cancer of the breast, it makes something swells in the breast and when they take to be checked, they diagnose it as cancer” (PA04).
	1.3: Cancer causes and risk factors	“We have many smokers in the community and that is why cases of Cancer of Esophagus are many” (KI01). “We have so far lost three people in our clan because of cancer. This may be an inherited disease and maybe transferred from one person to another through the clan or genetic” (PA06).
2. Community based surveillance and response to cancers	2.1: Prevailing cancer surveillance system.	“We depend on DHIS2, UCI data and those datasets speak directly into our surveillance system, which have lots of weaknesses in data quality issues, purity and accuracy. We need a system which can accurately pick the data on cancers and help in cancer surveillance” (KI04).
	2.2: Preparedness of the health systems to detect and manage cancer (policies)	“I think our healthcare system is not prepared at all. We have people who must travel 600km to get cancer care” (KI03).
	2.3: Challenges in cancer diagnosis and management	“You can’t imagine and tell someone suffering from cancer by looking at him, unless you go to the hospital for testing” (PA23). “Travelling from Soroti to Kampala takes about 6–8 hours. The patients don’t have the money to travel and don’t know the languages. The few that travel to Kampala remain in the veranda for months before being attended to” (KI05).
	2.4: Personal experiences with cancer care	“I came here to UCI in March 2025 for treatment, but since then I am still here. I have been staying in a tent for the past 5 months” (PA23). “I have been having one garden, but due to this sickness, it has made me to sell my plot for treatment. I have no place that I can settle a home, the children are young, they are not studying” (PA07).
3. Priorities in cancer research and dissemination	3.1: Areas to prioritize cancer research	“We need to do research in how we can improve services and access to cancer care in Uganda?” (KI03). “As I see, the cancer that should be researched in the villages is cancer of the breast and prostate. Those are the ones I think should be researched so fast” (PA08).
	3.2: Strategies for community engagement	“The first thing would be to make sure that we involve the people in the ground to work with and retain the knowledge even after the project has ended.” (KI06).

Theme 1: perceived causes and risk factors of cancer in the region

Category 1.1: understanding and misconceptions about cancer

Participants in the FGDs and dialogue meeting said that hearing the word cancer means “death”. The participants stated that cancer kills people, and it’s a heavy disease, an incurable disease with a lot of uncertainties.

“I really feel bad, people are dying because of cancer, but it seems the government is not responding to bring machines that detect cancer, more so among men” (PA02).

“The truth is, people have got scared about cancer, and now they know its death” (PA03).

On the other hand, the participants reported several myths and misconceptions about cancer and its causes, including witchcraft, poor hygiene, a virus or a worm and the use of contraceptives. They also expressed a general lack of knowledge regarding cancer as expressed by participants (PA05).

“People say its witchcraft” (PA04).

“According to women, they say it’s got as a result of a germ you contract when you go to the urinals and don’t clean after easing yourself, it enters in and eats one place inside and becomes a wound that later turns to cancer” (PA01).

“We need to get health workers to come to the villages to teach us about cancer. They say it’s a virus; we really don’t know if it’s a virus or a worm, so this needs to be clear. Others say its witchcraft” (PA05).

“Most people don’t know the existence of cancer. They lack information about it and whatever they don’t understand, they will say it is witchcraft” (PA20).

Category 1.2: common cancers in the region

The commonest cancers identified in the region and in the country by the key informants are cancer of the cervix, breast and prostate among adult females and males respectively. Other cancers in adults observed include Cancer of ovary, Throat (esophagus), penis and GI cancers (Stomach, liver pancreas). Kaposi sarcoma is becoming rare because of sustained HIV treatment program.

On the other hand, leukemias top childhood cancers, closely followed by the Hodgkin and non-Hodgkin lymphomas, in addition to Wilms tumor and osteosarcomas. These perceptions were expressed by participants below.

“The common cancers we get, especially for women is cancer of the cervix and cancer of the ovaries” (KI06).

“The commonest cancer we see here is cancer of the breast, but unfortunately, they come late when it has advanced” (KI05).

Similarly, the common cancers identified by the community members during the dialogue meetings and FGDs include cancer of the cervix, uterus, breast, prostate, throat, bone, blood, liver, pancreas, gallbladder, lungs and brain as elaborated by participants (PA01, PA07 and PA22).

“There is a cancer called lung cancer as a result of smoking” (PA01).

“Another one is cancer of the bones. A bone just gets broken. The person just stands and falls” (PA07).

“In Karamoja, someone has died of the cancer of the liver and cancer of the pancreas” (PA22).

Category 1.3: cancer causes and risk factors

Findings indicate varied views from participants on the causes and risk factors of Cancers. Most of the cancers in Uganda have no known risk factors. However, Participants expressed that a significant number of cancers such as Cancer of cervix, liver, Kaposi sarcoma, Burkitt's etc. are associated with infections. Furthermore, early sexual exposures, early marriages and having multiple sexual partners predispose girls to HPV and eventually cervical cancer, as well as genetics play a big role in cancer causes.

Participants highlighted behavioral risk factors such as high alcohol intake, smoking and hunger (in Karamoja) as some common risk factors. In addition, they suggested that the foods eaten such as ground nuts and silver fish may contain large quantities of aflatoxins which are known to be carcinogenic. Other participants expressed that environmental risk factors such as staying near water bodies could be predisposing community to schistosomiasis and risky sexual behaviors. These views are supported by excerpts from key informants below.

“Our girls get married early; they end up with multiple sexual partners as a result of that early marriage” (KI06).

“The district is surrounded by water, so most of the predisposing factors lie around the water. Eg So many do fish and are predisposed to schistosomiasis, leading to liver cirrhosis and cancer of liver” (KI02).

“The risk factors for cancers are not really known, but some people think that the type of food they eat and also blame family planning methods” (KI05).

“Cancers have specific etiologies e.g. cervical cancer is linked to HPV, whereas for breast cancer the etiology is not very clear. Some of the GI cancers are caused by heavy alcohol consumptions e.g. Cancer of stomach, liver, pancreas etc.” (KI04).

“Many cancers in Uganda are associated with infections e.g. Cancer of cervix, Kaposi Sarcoma and liver cancers.” (KI03).

Community members highlighted divergent perceptions on cancer causes, and risk factors and these include; alcohol consumption, eating fried food, cigarette smoking, or smoking from firewood, genetics/inherited/family disease, bleaching products, producing many children and some treatment modalities such as X-rays. These were elaborated in the following excerpts from participants.

“As a man, when you take a lot of cigarette and marijuana as well as that thing they put under the tongue, (called clock or Kuber), it can cause cancer” (PA03).

“Doctors teach that what causes cancer of the cervix is conceiving rapidly, before the wounds heal from the previous delivery, a mother again conceives so fast and at the end she starts bleeding and gets cancer of the cervix”. (PA02).

“Some people say you can get cancer when you eat fried food or when you get infections such as candida” (PA21).

Theme 2: community based surveillance and response to cancer

Category 2.1: prevailing cancer surveillance system

The participants stated that there is no stand-alone cancer surveillance system in the country and currently cancer surveillance depends on DHIS2 and health facility data which have lots of weaknesses including incompleteness and inaccuracy. Cancer surveillance in other countries is done through cancer registries, but Uganda has only Kampala cancer registry, which fails to capture the unique etiological factors of cancers in rural settings. Only cancer of the cervix is being surveyed currently, through donor funding. The health workers also lack information on cancer diagnosis and surveillance. These were elaborated in the following excerpts from the participants.

“We do some occasional outreaches, but we don't have a well laid down surveillance strategy to identify all the cancer cases in the region” (KI06).

“The only surveillance we are doing currently is for Cancer of Cervix, where we are screening all women in the reproductive age for cancer of the cervix. The rest of the cancers have no surveillance system.” (KI01).

“Cancer surveillance is done mainly through population-based cancer registry, we have no cancer registries for the rural and hard to reach and so we can’t capture the cancer etiological agents for these communities” (KI03).

There is need for community sensitization for cancers in the entire region, through conducting community screening surveys and testing those who come for the medical camps. Involvement of community team leaders such as village health teams (VHTs), Local Council I (LCIs), traditional and church leaders in cancer surveillance should be encouraged, while using the existing health care delivery system for cancer surveillance. The community case definitions of common cancers should be refined and the capacity of the community workers (VHTs) built to detect cancers at community level. There is a need for collaboration with Uganda Bureau of Statistics (UBOS) to study the population dynamics and demographic indicators which can then be used for cancer surveillance. These were elaborated in the following participant excerpts.

“We can use our healthcare delivery system infrastructure to do a reasonable cancer surveillance, staff like the [Village Health Teams] VHTs and community health workers can help in capturing the cancer information” (KI03).

“If we could have more medical camps in the community, this could help us to sensitize and screen the community, and this would improve our index of suspicion” (KI01).

Category 2.2: preparedness of the health systems to detect and manage cancer (policies)

Health facilities are ill-prepared to respond to the growing burden of cancers. Higher health facilities such as district hospitals and RRH can collect samples and refer for investigation but are not able to treat patients after the diagnosis. The referral systems are very poor and patients get lost along the way, with no feedback mechanism. There is lack of knowledge among the health workers on cancer diagnosis and management. The infrastructure does not allow for a good diagnostic space, despite having some trained health workers. The policies that exist are not sufficient and there are no instruments to implement. The National Cancer Control Plan is under development and an NCD law is being strengthened to regulate substance use.

“We are not prepared as much as we should, the best we can do is taking biopsies and sending to Kampala for histology to be done. We are unable to do most of the treatment required” (KI06).

“We are deficient in policies for most of the cancers except cervical cancer which has the test and treat policy and its being supported by the donor funds” (KI04).

“This is sub-Saharan Africa where resources are very limited. This leads to limited supplies, human resource among others” (KI04).

“The dissemination and implementation of the few policies we have in place is still very poor” (KI03).

“We need the health workers to be skilled and provided with diagnostic equipment.” (KI01).

“We have specialists, but all working in a health Centre IV, with no facility to support diagnosis” (KI02).

“We need to train the VHTs to ensure that they have some knowledge about the cancer and conduct community drives to create awareness on cancers” (KI02).

Category 2.3: challenges in cancer diagnosis and management

Participants in the FGDs and Dialogue meeting generally agreed that it’s difficult to tell from sight that someone is suffering from cancer. However, they highlighted some common observations which point towards cancer or a serious disease. These included chronic wound, which is taking long to heal, skin changes, too much bleeding for women, and chronic back pain.

“It’s difficult to know its cancer but there are signs that come up and you know its cancer, eg, if you develop a wound in the body and it takes long to heal, in the village, you will think its cancer and there is a virus building up from that area” (PA10).

“The skin can change color, the wound that doesn’t cure, too much bleeding for women” (PA09).

The challenges in cancer diagnosis and management identified by the key informants include lack of equipment for screening cancer, late presentation and lack of sensitization. There are a lot of missed opportunities in the early stages, poor linkages and referral to treatment and inadequate knowledge and skills amongst the health workers, coupled with resource constraints, including human resources for health.

Failure to seek care and support when referred to UCI due to high level of poverty. Having no medications in the facility within the region. Having only two cancer centers in the country, that is UCI and Gulu as satellites and no funding to build adequate infrastructure.

"Many times, someone comes and tells you I have been to this place, that place and so on but there was nothing done to help the patient. The health workers don't know what to look out for even though there is a lot of cancers around" (KI06).

"We rarely reach diagnosis of the Cancer of Liver because majority of them come late with Cirrhosis and die before the diagnosis is done" (KI01).

"One of the main challenges is the knowledge and skills gaps among the health workers and community members. There are many health workers who think cancer is an infection" (KI03).

"When you tell a patient that you are suspecting cancer and they need additional investigation, they get worried and decline the test." (KI01).

Category 2.4: personal experiences with cancer care

Many of the participants who had cancer shared their experiences which included frequent visits to the hospitals before a diagnosis was made. They received other prior treatments with no improvements until when their samples were taken for analysis at Soroti University, diagnosed with cancer and referred to treatment. There was delayed diagnosis in most cases for cancer patients. Some of the participants' experiences are the following.

"I had some wounds around my private parts which were itching, went to the health center and was given medication, it cleared a bit. It again started itching after sometimes, I went back to the health centre, they gave me the same medication which didn't resolve the wound, instead I started getting some pus. I went to the pharmacy, the nurse tried to treat for additional one month, with no improvement, that is when I was referred to the hospital, and then eventually to Soroti university which tested my sample and found that it was cancer" (PA13).

"My sister started feeling pain under her feet, she was rushed to Serere HCIV, some meat samples were cut off and taken to Mulago for investigation, but the results never returned and she continued feeling intense pain. After some time, she improved and was discharged from the health centre, but we continued going back to check for results and another painful swelling came up around the pelvis, the doctor in Serere again removed another sample, but with no results. We continued to treat the wound for 4 months and it was getting worse, until when we were referred to Soroti Hospital which picked samples and took to Soroti University which eventually confirmed the diagnosis" (PA14).

"For me, the blood was picked from Karamoja and sent to Kampala for testing, I was told to go back to the hospital after results have returned from Kampala. I

went to Matany in September, they picked my samples and the result returned in January 2025" (PA23).

Notably, patients were referred to Mulago for further treatment following a cancer diagnosis, with many hesitations and incapacity to go to Mulago due to many social and economic challenges leading to delayed care and treatment. Clearly, people who are diagnosed with cancer are financially not prepared to respond to the disease and its treatment demands. This leads to catastrophic expenditure and abject poverty that the family cannot meet the basic needs like feeding and educating children. These arguments are supported by the views of participants below;

"Dr told me that my patient has cancer and so we must go to Mulago within one month to avoid the cancer spreading." (PA12).

"I came here to UCI in March 2025 for treatment, but since then I am still here. I stay in a tent for the past 5 months" (PA23).

"My patient was taken to Serere HCIV, where he was referred to Soroti and then Mulago Hospital. The situation in Mulago wasn't immediate as we were told we would be seen after one week, so we returned home and the Mzee refused to be taken back to Mulago, because he believed he would die on the way and He eventually died after 1 month of return from Mulago" (PA15).

"I attended a certain burial of a rich man who had died of cancer in our village. He had a very huge kraal, but cancer reduced it" (PA 18).

"I have been having one garden, but due to this sickness, it has made me to sell my plot for treatment. I have no place that I can settle a home, the children are young, they are not studying" (PA07).

"It's quite expensive, takes a toll on you. It's an economic and emotional burden to you. In fact, it's a disease of the rich" (PA21).

Theme 3: priorities for cancer research and dissemination

Category 3.1: areas to prioritize cancer research

The key informants suggested areas of research priorities to be epidemiology, distribution and etiology of cancer in this region, including the incidence studies and geographical mapping of these cancers. They suggested conducting cancer disease surveillance at the landing site to understand the patterns of cancers in these areas. They also suggested building the capacity of the health workers on cancer screening, improving cancer care in Uganda and creation of awareness about cancer in the community.

"We have a lot of water bodies here; we need to investigate to what extent these waters lead to can-

cers e.g. a lot of people come with liver cirrhosis, could it be due to cancers?" (KI02).

"We need to do research on how we can improve care and access to cancer care in Uganda?" (KI03).

"We should create awareness about cancer in the community by ensuring they are sensitized but also ensure that the services for screening and treatment are available" (KI05).

The participants further suggested investigating the contribution of the locally available foods and environment to cancers, e.g. silver fish, water bodies etc. a focus on population-based registry for unique populations in Uganda and strengthening cancer surveillance systems.

"I think we need to look for the foods that we are eating, in the fishing community, we have silver fish which is known to have a lot of aflatoxins" (KI02).

On the other hand, the participants of dialogue meetings and FGDs suggested that research should be prioritized on cancers of blood, prostate, cervix, breast, throat and lungs.

"As I see, the cancer that should be researched and disturbing people behind in the village is cancer of the breast and prostate. Those are the ones I think should be researched so fast" (PA08).

Category 3.2: strategies for community engagement

Participants suggested working with the stationed health workers and the local political and traditional leaders in the community for continued community engagement. They also suggested continued community dialogue meetings, sensitization on radios and health education in the health facilities. They further suggested using the leadership structures in the community, such as VHTs, LCIs, LCIIIs and cultural leadership for community engagement. In addition, the participants suggested making use of cancer survivors to sensitize and engage the community. The participants of the FGDs and dialogue meeting further suggested the use of community radios, churches, community barazas or other gatherings and social media to disseminate the research findings.

"In this area, it is very difficult to do anything without involving the lower area political leadership e.g. LCIs, and traditional leaders. They are highly trusted for any community work" (KI06).

"The best way to engage the community is to use them themselves. Do community meetings, get their opinions, give right information and use the leadership structure in the community like VHTs, LCI etc. to foster community cooperation into the study." (KI02).

"The most effective way to mobilize and have the information reach to the people is through the VHTs. You can empower these people, and the response is always very fast" (KI05).

Discussion

This study was a consultation for Wellcome Trust research grant application for the Discovery Awards scheme. While this study informed a grant application, its findings stand as independent qualitative evidence on cancer research priorities in the region. Its aim was to understand the perspectives of the community members, health workers and policy makers and to obtain their insights into cancer prevention, control and research in Northeastern Uganda. The study explored the perspective of these stakeholders and their insights into the common cancers seen in the region, cancer risk factors, surveillance systems, treatment and prevention options and the priorities for cancer research.

Perceived causes and risk factors to cancer

The commonest cancers in the region identified by the stakeholders are cancer of the breast, cervix and prostate among adults while leukemia tops childhood cancers. This qualitative assessment of common cancers by the key informants and other community stakeholders is in line with previous findings in the region and in Uganda where cancer of the breast, prostate, esophagus and cervix are the top 4 cancers [10, 14]. The regional cancer spectrum in Uganda indicates Teso is among the top 6 most affected regions and Karamoja as the least affected regions [10, 14]. This low burden reported may be due to the lack of cancer registries and treatment centers in the region as all the cancer cases identified are referred to Uganda Cancer Institute and their incidence reported under the Kampala cancer registry [10].

In the neighboring region of Northern Uganda, cancers of the cervix and non-Hodgkin Lymphoma were most common among females, and non-Hodgkin Lymphoma, Kaposi Sarcoma and prostate were more common in men [26], quite unique from what is observed by the participants in our study. Most of the cancers in Uganda have no known risk factors, however, several of them are associated with infections. Cervical cancer, Burkitt's Lymphoma, Kaposi Sarcoma, Hepatocellular carcinoma and Cancer of Esophagus among others are all known to have infectious origin [26, 27]. These cancers were identified by the stakeholders as leading cancers in the region.

It is therefore important to prioritize cancers with infectious origin for prevention and control. Interventions to control infections such as HPV and HepB vaccination should therefore be prioritized. Unfortunately, HPV vaccination in the region and the country is sub-optimal [28, 29]. Other prevention measures such as

early screening and treatment for cancers are low in the Northeastern region and Uganda as a whole [11, 12, 30].

The epidemiology of some of these cancers tends to follow certain patterns, with genetics, environmental and behavioral factors such as high alcohol intake, smoking and multiple sexual partners/early marriages are well documented risk factors for some common cancers [31, 32]. Targeted research and interventions to reduce cancer risk factors are urgently needed in the subregion.

Community-based surveillance and response system to cancer

There is no stand-alone cancer surveillance system in the country and currently it depends on district health information system (DHIS2) and health facility data which have lots of weaknesses including incompleteness and inaccuracy. Research done using routinely collected data in Uganda and South Africa have highlighted the need to improve data completeness and quality [33, 34]. There is need therefore to make deliberate efforts to improve cancer surveillance system by creating and organizing a community-based cancer surveillance database. The community-based cancer surveillance in Uganda is not currently happening, with only two population-based cancer registries in Kampala and Gulu which rely on data generated from the health facilities.

The health workers also lack information on cancer diagnosis and management. Other studies done in Turkey have demonstrated the general lack of knowledge by health workers regarding cancer prevention and control [35, 36]. There is need to invest in capacity building of the health workers to rapidly detect cancers at the early stages as has been proposed by a team from UCI [37]. There is need for community sensitization and screening for cancers in the entire region to improve the rate of early detection and treatment. Most of the cancers diagnosed in Uganda are in advanced stages due to lack of early screening services [38, 39].

Involvement of community team leaders such as VHTs, LCIs, traditional and church leaders in cancer surveillance have been suggested by the stakeholders to be promoted and the community case definitions of common cancers should be refined and the capacity of the community workers (VHTs/CHEWs) built to detect cancers at community level. Communities play a critical role in disease identification and prevention. They have been successfully engaged in Uganda to prevent infectious diseases such as malaria, HIV and TB among others [40–42].

Health facilities in the region are generally ill-prepared to respond to the growing burden of cancers and other emerging diseases. This is a similar observation made earlier in Uganda and other SSA [5, 6, 43]. To adequately respond to cancer, the facilities need to comprehensively prepare to handle health education, prevention, screening, early detection and treatment of cancers. The referral

systems are very poor and patients get lost along the way, with no feedback mechanism. There is lack of knowledge among the health workers on cancer diagnosis and management. There is need to invest in training of health workers in the diagnosis and management of cancer. This will enable them to comprehensively attend to patients from the remote areas and promote early diagnosis.

There have been reported delays in cancer diagnosis across Uganda and other SSA due to several factors including knowledge gaps by the health care providers [38, 43]. The infrastructure does not allow for a good diagnostic space, despite having some trained health workers. The policies that exist are not sufficient and there are no instruments to implement. Some of the policies for cancer control adopted by the country include cervical cancer control strategy [13, 44, 45] which is heavily donor funded and not well disseminated.

Priorities for cancer research

Priorities for cancer research identified during this stakeholders' engagement include epidemiology and etiology of cancer, including the incidence studies and geographical mapping of these cancers. Conduct cancer disease surveillance at the landing site. Teso region specifically has numerous landing sites and the cancer disease burden in these areas are unknown, yet there are several risk factors to cancer. Investigate the contribution of the locally available foods and environment to cancers.

There is need to focus on population-based registry for unique populations in Uganda and strengthening cancer surveillance systems. Research on improving the cancer care in Uganda. Research on local treatment for cancer. The priorities of cancer research proposed in low and middle income countries include; reducing the burden of patients with advanced disease; improving access and affordability, and outcomes of cancer treatment; value-based care and health economics; quality improvement and implementation research; and leveraging technology to improve cancer control [8].

Study limitations

Our study had some limitations. The qualitative nature of the study could have led to subjectivity and researcher bias in the interpretation of the community perspectives. This was minimized by ensuring that at least 4 researchers conduct data analysis and reach a consensus on the findings. The participants insights and perspectives enlisted could be subject to social desirability bias. In addition, participants in the FGD and dialogue meetings and some key informants had very little knowledge on the existing cancer prevention and treatment policies and so it was difficult to examine the adequacy of these policies among the study participants.

Conclusion

This consultative study which was undertaken to inform a Wellcome Trust research grants application highlights the importance of an engaged participatory approach to identify research problems. Through this approach, the research team was able to accurately understand the research context, identify research issues, and priorities.

From this study, we have established that the community perceives cancer as an incurable disease with a lot of uncertainties, myths and misconceptions about its causes, including witchcraft, poor hygiene, a virus or a worm and the use of contraceptives. They also expressed a general lack of knowledge regarding cancers. The common cancer causes and risk factors they perceived included alcohol consumption, eating fried food, cigarette smoking, or smoking from firewood and genetics, with radios, newspapers, social media, television and health education by health workers being the common sources of information.

Health facilities are ill-prepared to respond to the growing burden of cancers. The referral systems are very poor, with patients moving long distances to referral sites and getting lost along the way. Cancer surveillance systems in the country are limited and rely on routinely collected data which have lots of weaknesses including incompleteness and inaccuracy.

Priorities for cancer research identified by this study include epidemiology and etiology of cancer, including the incidence studies and geographical mapping of these cancers, conducting cancer disease surveillance at the landing site and investigating the contribution of the locally available foods and environment to cancers.

There is need for community sensitization and screening for cancers in the entire region. Involvement of community team leaders such as village health teams (VHTs), local council I (LCIs), traditional and church leaders in cancer surveillance should be encouraged and the community case definitions of common cancers should be refined and the capacity of the community workers (VHTs) built to detect cancers at community level.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12885-026-16088-x>.

Supplementary Material 1.

Acknowledgements

The authors would like to acknowledge the support rendered by the District Health Officers of Northeastern Uganda who provided administrative clearance for this study and Management of Soroti University and Uganda Cancer Institute for providing seed funding which facilitated the data collection process and manuscript writing.

Authors' contributions

Conceptualization and Proposal Development: PI, JO, RO, AJ, EO, AM, LOO, WS. Data Collection: RO, LOO, EO, PI, AJ. Data Analysis: RO, HA, AJ, PI, LOO. Report writing and review: All authors wrote and reviewed the manuscript. Funding acquisition: RO, JO, AJ.

Funding

This study was funded by Government of Uganda, through Soroti University Research and Innovation Fund (SUNRIF) and Uganda Cancer Institute (UCI).

Data availability

All the data for this work is presented within the manuscript and its supporting information.

Declarations

Ethical approval and consent to participate

This study received ethical approval from Mbale Regional Referral Hospital Research and Ethics Committee (MRRH REC) reference No MRRH-2024-437 and registered with Uganda National Council of Science and Technology (UNCST), Reg No HS6508ES. The study followed the principles of declaration of Helsinki. All participants provided informed consent to participate in the study and to allow for zoom recording of the interview sessions. The recordings are kept secure on a password protected computer and only accessible to one study investigator, RO.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Received: 1 January 2026 / Accepted: 21 April 2026

Published online: 24 April 2026

References

- Bray F, Laversanne M, Sung H, Ferlay J, Siegel RL, Soerjomataram I, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin.* 2024;74(3):229–63.
- Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. *CA Cancer J Clin.* 2021;71(3):209–49.
- World Health Organization. Cancer key facts. World Health Organisation. 2025. Available from: <https://www.who.int/news-room/fact-sheets/detail/cancer>. Cited 29 Oct 2025.
- Lawa QO, Lawal I, Eigbefoh J, Aigbonoga DE, Lawal G. Cancer Care Gap: Examining Cancer Mortality-Incidence Rate Ratio in Sub-Saharan Africa. *JCO Glob Oncol.* 2024;10(Supplement1):35–35.
- Morhason-bello IO, Odedina F, Rebbeck TR, Harford J, Dangou J, Denny L et al. Cancer Control in Africa 1 Challenges and opportunities in cancer control in Africa: a perspective from the African Organisation for Research and Training

- in Cancer. *Lancet Oncol.* 2013;14(4):e142–51. Available from: [https://doi.org/10.1016/S1470-2045\(12\)70482-5](https://doi.org/10.1016/S1470-2045(12)70482-5).
6. Gugulethu Tshabalala, Blanchard C, Mmoledi K, Malope D, Neil DSO, Norris SA et al. A qualitative study to explore healthcare providers' perspectives on barriers and enablers to early detection of breast and cervical cancers among women attending primary healthcare clinics in Johannesburg, Sou. *PLOS Glob Public Heal.* 2023;1–18. Available from: <https://doi.org/10.1371/journal.pgph.0001826>.
 7. Rubagumya F, Carson L, Mushonga M, Manirakiza A, Murenzi G, Abdihamid O, et al. An analysis of African cancer research ecosystem: tackling disparities. *BMJ Global Health.* 2023;8:e011338. <https://doi.org/10.1136/bmjgh-2022-011338>.
 8. Pramesh CS, Badwe RA, Bhoo-pathy N, Booth CM, Chinnaswamy G, Dare AJ, et al. Priorities for cancer research in low- and middle-income countries: a global perspective. *Nat Med.* 2022;28:649–57. Available from <https://doi.org/10.1038/s41591-022-01738-x>.
 9. Matovu N, Mugisha NM, Jatho A, Charlene M. Colorectal cancer research priorities in Uganda: perspectives from local key experts and stakeholders. *Futur Oncol.* 2024;20. Available from: <https://doi.org/10.1080/14796694.2024.2416885>.
 10. Nakaganda A, Spencer A, Mpamani C, Nassolo C, Namboozee S, Wabinga H, et al. Estimating regional and national cancer incidence in Uganda: a retrospective population-based study, 2013–2017. *BMC Cancer.* 2024;24(1):1–11.
 11. Opito R, Tiyo Ayikobua E, Akurut H, Alwedo S, Ssentongo SM, Erabu WD et al. Factors associated with uptake and acceptability of cervical cancer screening among female sex workers in Northeastern Uganda: A cross-sectional study. *PLoS One.* 2025;20(1):e0312988. Available from: <https://doi.org/10.1371/journal.pone.0312988>.
 12. Ekinu J, Ayikobua ET, Icodu E, Akurut H, Akot OO, Oder S et al. Factors Associated with Cervical Cancer Screening Uptake Among Women Attending Outpatient Department in a Rural District Hospital in Uganda. A Cross-Sectional Study. *Int J Womens Health.* 2025;17(null):2603–11. Available from: <https://www.tandfonline.com/doi/abs/https://doi.org/10.2147/IJWH.S541935>.
 13. World Health Organization. Global strategy to accelerate the elimination of cervical cancer as a public health problem. Geneva; 2020. Licence CC BY-NC-SA 3.0 IG. Available from <https://www.who.int/publications/i/item/9789240014107>.
 14. Okongo F, Amuge C, Jatho A, Niyonzima N, Ogwang DM, Orem J. The regional cancer spectrum in Uganda: a population-based cancer survey by sub-regions (2017–2020). *Ecancermedicalscience.* 2024;1–16. Available from: <https://doi.org/10.3332/ecancer.2024.1782>.
 15. Jatho A, Tran BT, Cambia JM, Nanyingi M, Mugisha NM. Cancer risk studies and priority areas for cancer risk appraisal in Uganda. *Ann Glob Heal.* 2020;86(1):1–24.
 16. McLeroy Kenneth R, Bibeau Daniel S, Allan. Glanz Karen. An Ecological Perspective on Health Promotion Programs. *Health Educ Q.* 1988;15(4):351–77. Available from: <https://doi.org/10.1177/109019818801500401>.
 17. Bronfenbrenner U. The Ecology of Human Development. Experiments by Nature. Harvard University Press; 1979. Available from: <https://doi.org/10.2307/j.ctv26071r6>.
 18. Golden Shelley D, Earp Jo Anne L. Social Ecological Approaches to Individuals and Their Contexts: Twenty Years of Health Education & Behavior Health Promotion Interventions. *Heal Educ Behav.* 2012;39(3):364–72. Available from: <https://doi.org/10.1177/1090198111418634>.
 19. Krieger N. Epidemiology and the web of causation: Has anyone seen the spider? *Soc Sci Med.* 1994;39(7):887–903. Available from: <https://www.sciencedirect.com/science/article/pii/027795369490202X>.
 20. Becker MH. The health belief model and personal health behavior. *Health Educ Monogr.* 1974;2:324–473.
 21. Uganda Bureau of Statistics. National Population and Housing Census 2024_ Final report Final report. Vol. 1, UBOS. Kampala. 2024. Available from: <http://libdcms.nida.ac.th/thesis6/2010/b166706.pdf>.
 22. Sharan B, Merriam, Elizabeth J, Tisdell. *Qualitative Research. A guide to Design and Implementation.* 4th Editio. ebook: John Wiley and Sons Inc.; 2016. Available from: https://books.google.co.uk/books?id=JFN_BwAAQBAJ&printsec=froontcover&source=gbs_ge_summary_r&cad=0#v=onepage&q&f=false.
 23. Crotty M. *Foundations of Sociaal Research. Meaning and perspective in the research process.* London: Taylor and Francis Ltd.; 1998. Available from: <https://www.taylorfrancis.com/books/mono/10.4324/9781003115700/foundation-s-social-research-michael-crotty>.
 24. Mayne J. *The COM-B Theory of Change Model.* 2016.
 25. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Heal Care.* 2007;19(6):349–57.
 26. Okongo F, Ogwang DM, Liu B, Maxwell Parkin D. Cancer incidence in Northern Uganda (2013–2016). *Int J Cancer.* 2019;144(12):2985–91.
 27. Blackadar CB. Historical review of the causes of cancer. *World J Clin Oncol.* 2016;7(1):54–86.
 28. Nagudi LD, Kateregga J, Munguiko C, Akurut H, Opito R. Uptake and Completion of Human Papilloma Virus Vaccination by Adolescent Girls Attending Primary Healthcare Facilities in Soroti City, Northeastern Uganda; A Cross-Sectional Study. *J Nur Healthc.* 2025;10(1):1–8.
 29. Isabirye A, Mbonye M, Asiimwe JB, Kwagala B. Factors associated with HPV vaccination uptake in Uganda: a multi-level analysis. *BMC Women's Health.* 2020;20:145. <https://doi.org/10.1186/s12905-020-01014-5>.
 30. Ekwan R, Bua E, Nantale R, Opito R, Abingwa P, Sserwanja Q et al. Uptake of prostate cancer screening and associated factors among men aged 50 years and above in Lira city, Uganda: a cross-sectional study. *BMC Public Health.* 2023;23(1):432. Available from: <https://doi.org/10.1186/s12889-023-15348-w>.
 31. Wu S, Zhu W, Thompson P, Hannun YA. Evaluating intrinsic and non-intrinsic cancer risk factors. *Nat Commun.* 2018;9(1). Available from: <https://doi.org/10.1038/s41467-018-05467-z>.
 32. Lewandowska AM, Rudzki M, Rudzki S, Lewandowski T, Laskowska B. Environmental risk factors for cancer - review paper. *Ann Agric Environ Med.* 2019;26(1):1–7.
 33. Ocen E, Opito R, Tegu C, Oula A, Olupot PO. Severe malaria burden, clinical spectrum and outcomes at Apac district hospital, Uganda : a retrospective study of routine health facility- based data. *Malar J.* 2023;1–8. Available from: <https://doi.org/10.1186/s12936-023-04761-6>.
 34. Thabethe SS, Mathews VE. Quality of routine health data in DHIS2 in South Africa: Eastern Cape province from 2017–2020. *South Afr J Inf Manag.* 2024;26(1):1–12.
 35. Kaya C, Üstü Y, Özyörük E, Aydemir Ö, Şimşek Ç. Demirci Şahin A. Knowledge, attitudes and behaviors of health workers about cancer screening. *Ankara Med J.* 2017;17(1):73–83.
 36. Soylar P, Özer A, Doğan Yüksek Ö, Ulucan M. Knowledge, Attitude, and Practice Regarding Cancer Screening Tests Among Health Workers in a University Hospital in Turkey. *J Cancer Educ.* 2020;35(4):718–23.
 37. Jatho A, Mugisha NM, Kafeero J, Holoya G, Okuku F, Niyonzima N, et al. Capacity building for cancer prevention and early detection in the Ugandan primary healthcare facilities: Working toward reducing the unmet needs of cancer control services. *Cancer Med.* 2021;10(2):745–56.
 38. Achan J, Kasujja FX, Opito R, Wabinga H, Orach CG, Mwaka AD. Factors associated with diagnostic and pre-treatment intervals among breast cancer patients attending care at the Uganda Cancer Institute: A cross-sectional study. *Cancer Med.* 2023;12(19):19701–13.
 39. Lacika JL, Wabinga H, Kagaayi J, Opito R, Orach CG, Mwaka AD. Diagnostic and pre-treatment intervals among patients with cervical cancer attending care at the Uganda Cancer Institute: a cross-sectional study. *BMC Womens Health.* 2023;23(1):633. Available from: <https://doi.org/10.1186/s12905-023-02785-3>.
 40. Kisakye NI, Maltezou HC, Mugarura R, Jonathan AN, Etyang C. Knowledge and practices of anti-malarial treatment for children under five years among village health teams in Kasese District, Uganda: A cross-sectional study. *IJID Reg.* 2025;17:100749. Available from: <https://www.sciencedirect.com/science/article/pii/S2772707625001845>.
 41. Siya A, Mafigiri R, Migisha R, Kading RC. Uganda mountain community health system—perspectives and capacities towards emerging infectious disease surveillance. *Int J Environ Res Public Health.* 2021;18:8562. <https://doi.org/10.3390/ijerph18168562>.
 42. Musoke D, Lubega GB, Twesigye B, Nakachwa B, Brown MO, Gibson L. Enhancing the capacity of community health workers in prevention and control of epidemics and pandemics in Wakiso district, Uganda: evaluation of a pilot project. *BMC Prim Care.* 2024;25(1):260. Available from: <https://doi.org/10.1186/s12875-024-02522-1>.
 43. Lott BE, Halkiyo A, Kassa DW, Kebede T, Dedefo A, Ehiri J et al. Health workers' perspectives on barriers and facilitators to implementing a new national cervical cancer screening program in Ethiopia. *BMC Womens Health.* 2021;1–14. Available from: <https://doi.org/10.1186/s12905-021-01331-3>.
 44. Uganda Ministry of Health. *The national cervical cancer prevention and control strategic plan.* Kampala; 2018.
 45. World Health Organization. *WHO guideline for screening and treatment of cervical pre-cancer lesions for cervical cancer prevention, second edition.* Hum reproductive program. 2021;101:2653–7.

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