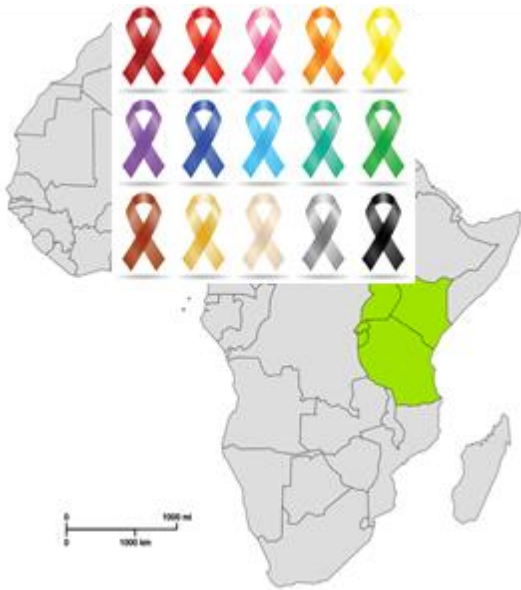




Regional Program for Cancer Registries in East Africa



user

Draft case studies



EAST, CENTRAL AND SOUTHERN AFRICA HEALTH COMMUNITY

Fostering Regional Cooperation For Better Health

Kenya

Establishment of a National Cancer Registry to Increase Coverage in Kenya: Lessons from a de-centralized approach

Background

Kenya has a population of 50 million people, as per 2018 projections [1]. Cancer is one of the leading public health challenges in Kenya, in terms of morbidity, mortality and economic impact. The estimated annual incidence is 47887 cases and 32,987 deaths [2]. Cancer diagnosis and management is undertaken at two national referral facilities, five private facilities, two faith-based facilities and ten county referral facilities recently equipped to offer chemotherapy. Kenya has previously been served by three regional population-based cancer registries (PBCR), the Nairobi, Eldoret and Kisumu cancer registries [3].

Registry	Type	County
Nairobi	PBCR	Nairobi
Eldoret	PBCR	Uasin Gishu
Kisumu	PBCR	Kisumu
Kenyatta National Hospital	HBCR	Nairobi
Nyeri	HBCR	Nyeri
Embu	HBCR	Embu
Kakamega	HBCR	Kakamega
Nakuru	HBCR	Nakuru
Meru	HBCR	Meru
Laikipia	HBCR	Laikipia

The Kenya National Cancer Control Strategy 2017-2022 (NCCS) lays emphasis on cancer registration and surveillance, and envisions setting up of a national, population-based cancer registry as well as regional/county based registries [4]. Additionally, the Cancer Prevention and Control act, enacted in 2012, provides for establishment of a national population-based cancer registry by the National Cancer Institute of Kenya and mandatory reporting by facilities diagnosing or managing cancer [5,6].

While currently available registries provide estimates for the country, the information has been limited by details on the regional/county burden of cancer. With a new constitutional dispensation, emphasis was placed on organization and management of health services at the county level, including surveillance and data utilization; this made data disaggregation to the level of counties of prime importance [7]. Setting up of a national cancer registry system will provide continuous data on cancer burden in Kenya identify key areas of cancer research and enable the realization of the objectives stated in the NCCS.

Interventions

The country set up a national cancer registry (KNCR) with regional registries based at the ten chemotherapy centers as well as the existing registries feeding into it. The current project was aimed at supporting the national and regional registries to improve registration and reporting and provide regional estimates of the cancer burden. Under the World Trust Bank Regional Program

for Cancer Registries, 25 cancer registrars employed at five of the ten regional centers have been trained as well as equipping of the national cancer registry office.

Preliminary Results

In 2018, 12,292 cancer cases were reported; 7940 (64.6%) among females. **Figure 1** shows the burden distribution in terms of cancer type; the leading cancers in burden and mortality are cervix and esophagus.

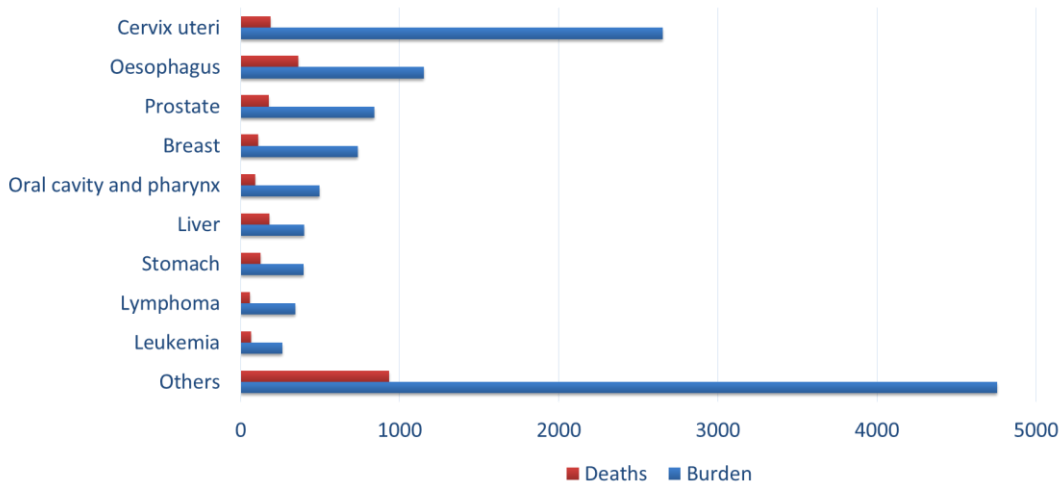


Figure 1: Cancer incidence and mortality, Kenya, 2018 (n=12,292)

Males had higher cases reported in the pediatric age-group, while females had number of cases reported for the 30-49 years age group (**Figure 2**).

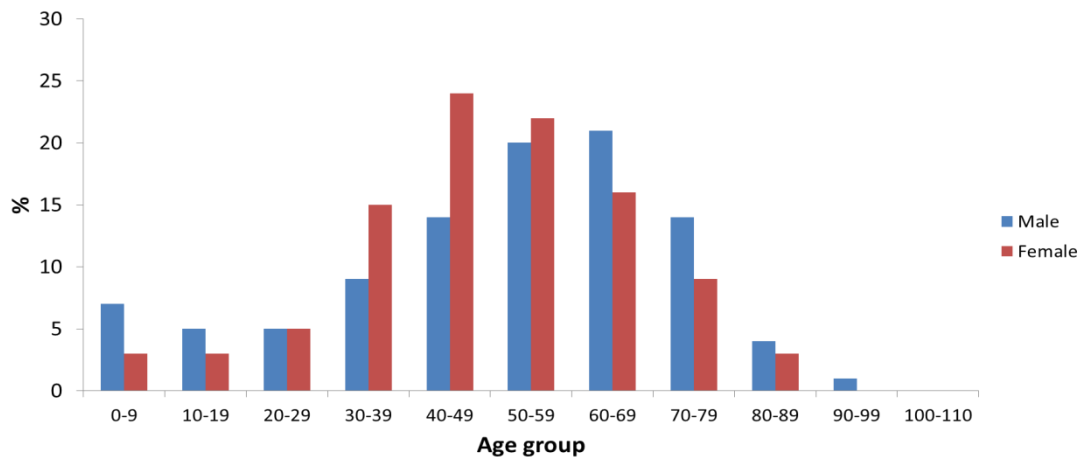


Figure 2: Cancer burden by age and sex, Kenya, 2018

Most of the cases reported clustered around the central and western counties of the country (**Figure 3**).

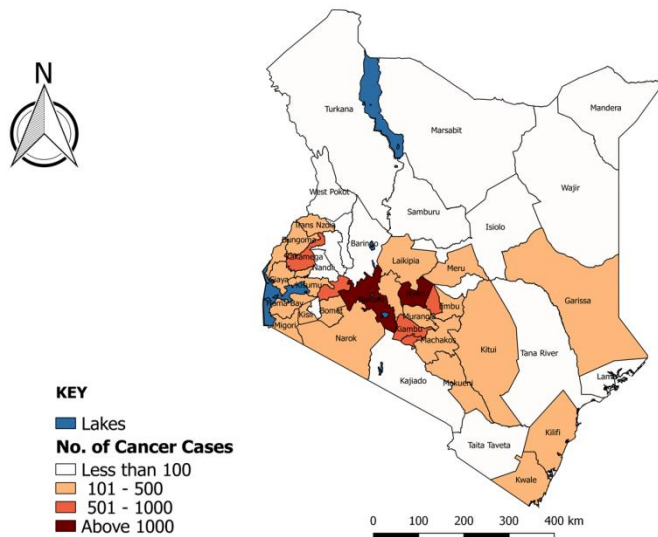


Figure 3: Cancer burden by county, Kenya, 2018

Lessons and best practices

Through this process, we recognized the importance of partnership, role of stakeholder involvement and efficacy of wider collaborations with other state departments. Additionally, a decentralized structure of a national registry fits a devolved system of healthcare provision, like the case with Kenya.

Challenges

- Ensuring a shared vision and mission for cancer registration in a devolved system of governance
- Cancer registrars not ring-fenced for cancer registry work/lack of dedicated registry staff as well
- Inadequate mentorship and infrastructure to support the registries in some of the regional centers

Conclusion

Regional-based registries, feeding into a national one offers opportunities for increasing coverage, ensuring sustainability and process ownership as well as data utilization by the counties.

Recommendations and future directions

- Governments to ensuring dedicated staff are assigned to the registries.
- Continuous technical support for the county registries.
- Training and regular mentorship forums are necessary to ensure the regional cancer registration hubs maintain and improve cancer registration.
- Making the remaining regional registries functional will enhance registry coverage in Kenya.

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Burundi

Early steps towards developing Burundi population-based cancer registry

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Background

The current population of Burundi according to the latest United Nations estimates is 12,627,680, comprising 6,200,595 (49.1%) males and 6,427,085 (50.9%) females. According to Globocan, Number of new cancer cases in 2018, both sexes, all ages are 8682, with 1859 (21.4%), Kaposi sarcoma 838(9.7%), prostate754 (8.7%), breast 634(7.3%), esophagus 520(6%), others cancers 4077(47%) these results was made through neighbor countries data.

Burundi is facing challenges in its systematic program that collects and collates cancer data (anatomopathological laboratory is out of order for three years and cancer treatment is not yet initiated except palliative care). Patients are managed in neighboring countries (Kenya, Rwanda, Uganda...) or abroad (India, USA etc.). some patients will come back with prescription of chemotherapy to be administrated in one of our private hospitals known as KIRA in Bujumbura. So far, some activity in cancer control are in progress and among them:

- Cervical cancer free screening (VIA and CRYOTHERAPY for preneoplastic lesions) are being done in 4 provinces with vision to extend to the national level.
- HPV immunization for girls between 9-13 years as demonstration pilot in two district hospital from 2016 and extend to the national level

- The East African Public Health Laboratory Network Project (EAPHLN)/ World Bank purchased new equipment for the only anatomic pathology laboratory in the country to be delivered by May 2019.

Intervention

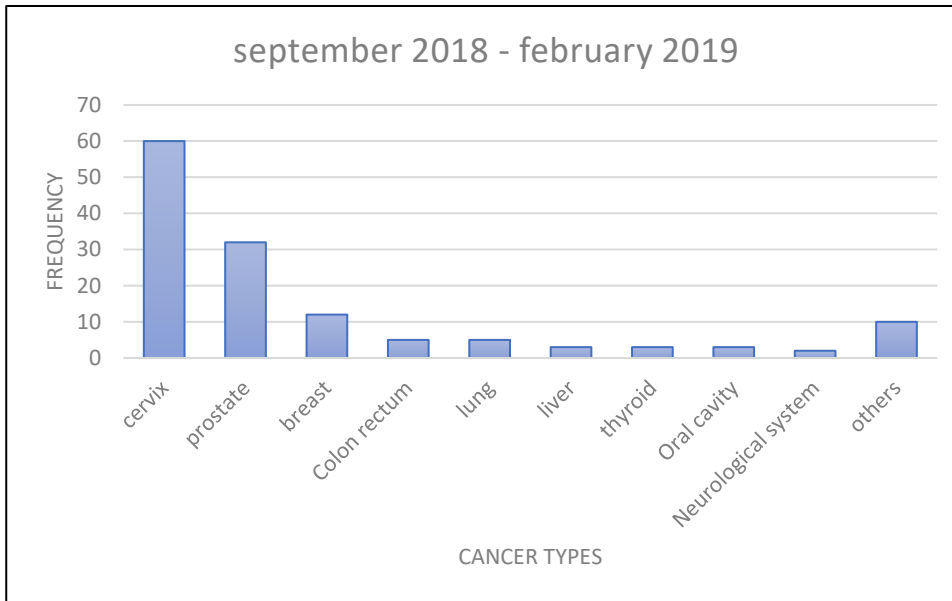
The government of Burundi have already engaged in cancer control by implementing the cancer policy and strategy plans. The Implementation of Bujumbura population-based cancer registry since January 2019 is also one major activity in cancer control program. The targeted population is 1053099, with 550191(52.3%) males and 502908(47.7%) females, Bujumbura PBCR is covering 3 health districts, with 4 public hospital and 12 private hospitals. , the Bujumbura PBCR, has a challenge to collect data, to provides reliable results, and a full picture of cancer in Bujumbura for health political decisions which are actually impossible to be made due to absence of any source of sustainable information on cancer situation.

Preliminary results

The total number of new cancer cases registered from September 2018 to February 2019 (6 months) in 5 health facilities of Bujumbura city is 135, comprising 55 males and 80 females. The leading cancer in males is prostate with 32(23.7) and in females, cervical cancer is the most frequent type of cancer 60 (44.4%).

Table 1: Types cancers recording in the Bujumbura registry

Cancer types	frequency	%
Cervix	60	44.4%
Prostate	32	23.7%
Breast	12	8.8%
Colon rectum	5	3.7%
Lung	5	3.7%
Liver	3	2.2%
Thyroid	3	2.2%
Oral cavity	3	2.2%
Neurological system	2	1.4%
Others	10	7.4%



Best or promising practices

Though, the cancer registry is still in its initial steps, the lesson we learned so far, is that cancer registry is very important because the data generated by the registry help in sensitization, prevention, treatment and cancer control. But the Bujumbura PBCR, will only provide information on Bujumbura cancer situation, and in the coming days the extension of population-based cancer registry to other provinces should be in our future perspective in order to get a full picture of cancer burden in Burundi.

Challenges:

- Limited cancer diagnostic services such as histopathology for confirmation of cancer cases.
- Inadequate functional cancer care facilities in the country which obliges patients to go abroad for treatment and no longer available in our data base.
- Limited trained health professional in oncology (radiotherapy, surgical oncology, medical oncology, pediatric oncology, gynecological oncology....) still to be increased in number and capacity.

Conclusion and recommendation

Cancer control in Burundi is in its early steps, after 3 months of the existing of Bujumbura PBCR, the few data already collected shows that cancer of cervix is leading with 60 and prostates leads with 32 in the 135 cancer cases collected in 5 hospitals for a retrospective period of 6 month. This also means that the cancer registry is unavoidable in cancer control program; however, it still needs more experienced staff in data collection, data entry and data analysis in Canreg5. In perspective, the support and collaboration from partners of development and other cancer registry are crucial for perennisation and development of Bujumbura PBCR. The implementation of other population-based cancer registries in other provinces is very important for cancer control in Burundi.

References

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2. Globocan 2018

Rwanda

Rwanda is laying a strong foundation towards the establishment of a National Cancer Registry

Introduction

In Rwanda, reliable data on cancer epidemiology are limited; hospitals are reporting aggregate numbers through Health Management Information System (HMIS) with many duplications as cancer patients navigate through different facilities seeking for care. Current estimates of cancer burden are based on the distribution of cancers from neighbouring countries; according to Globocan 2018, around 10,704 new cancer cases and 7,662 cancer related deaths are estimated in Rwanda.

Cancer diagnosis and treatment services exist in University Teaching Hospitals (5 centers) and consist of Anatomopathology, Surgery, Chemotherapy and Radiation therapy.

Rwanda is finalizing the development of the first National Cancer Control Plan, 2019-2024 that will be focusing on establishing strong cancer prevention, early detection, diagnosis, treatment and palliation services, all bounded by an effective M&E system based on a National Cancer Registry.

Prior to the 1994 genocide, Rwanda had a cancer registry based at the University Hospital at Butare (CHUB), later on there was initiation of another cancer registry owned by a non-governmental organization collecting information in teaching hospitals but stopped in 2013 when the funding was phased out.

In light of the above, Rwanda has initiated the establishment of a government owned National Cancer Registry that will provide reliable data on cancer epidemiology in Rwanda, thus informing cancer control policies and plans. The implementation will be done into phases starting with establishing Kigali Population Based Cancer Registry hosted under the Ministry of Health/ Rwanda Biomedical Center, Cancer Control Unit.

Intervention

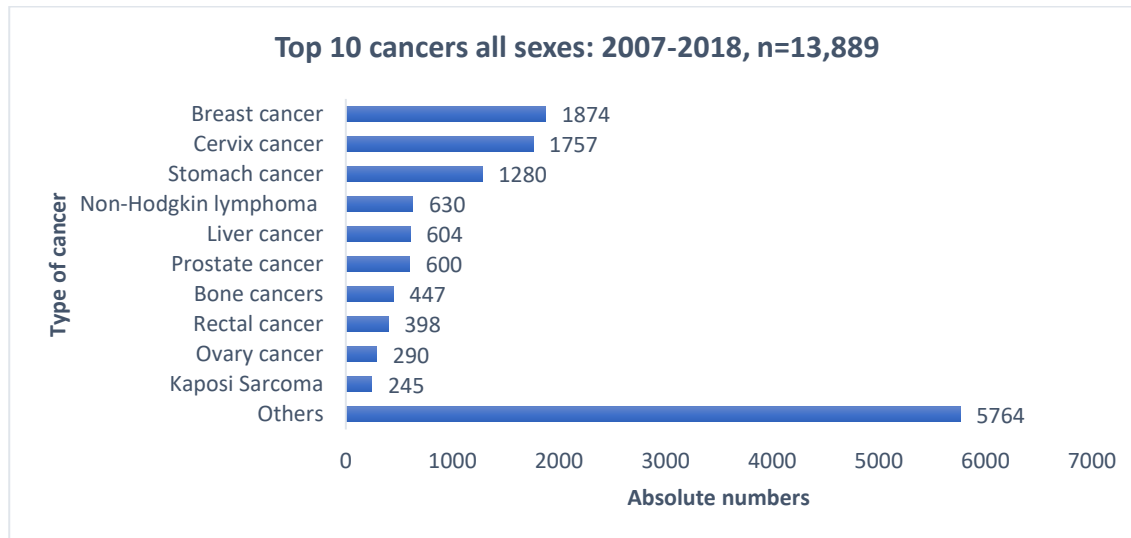
The City of Kigali (CoK) is the capital city of Rwanda with a population of 1.13 million (Census, 2012) now projected at 1,3 million people on the size of 730 km². The City of Kigali has got 144 main health facilities (Hosp, HCs and Private Clinics), among them, 25 have cancer care and treatment services (either screening, diagnosis, treatment or follow up).

In collaboration with different stakeholders, the establishment of Kigali Population Based Cancer Registry (KPBCR) started in July 2018 with creation of a cancer registry office at RBC run by 4 staff, training of cancer registrars from RBC and focal persons from registry data collection sites, around 65 people got a basic training on cancer registration. Central level cancer registrars got advanced training on cancer registration and are now mentoring cancer registry focal persons in data collection sites.

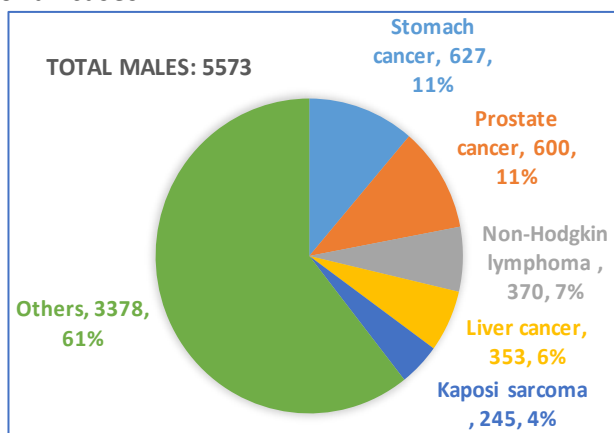
The registry is using active data collection in big hospitals combined with passive data collection by focal persons in small clinics and district hospitals. In addition to facilities based in the CoK, the registry is collecting information from 4 addition centers outside Kigali where residents of Kigali are also being treated

Results

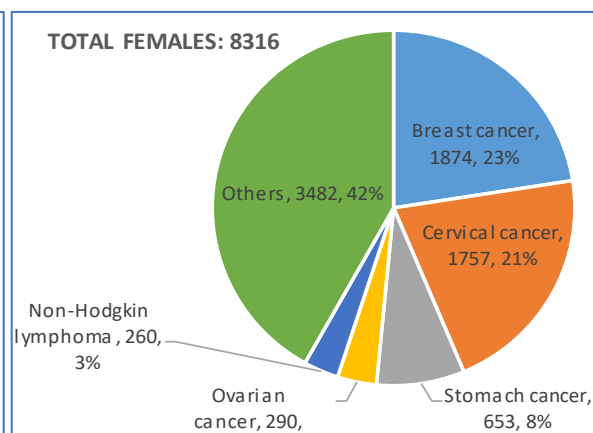
Over the course of 9 months of implementation of the cancer registry, we retrospectively (from 2012) abstracted data from 4 big cancer sites and so far, 16,313 cases have been abstracted. The data entry in the CanReg5 has also been initiated and 8,173 cases have been entered in the data base on top of 5,716 cases that were already in the system, making a total of 13,889 cases.



The preliminary results show that the top two incident cancers are breast and cervix. According to gender, the majority of cases are found in females representing 60% (8,316) of all cases.



Top 5 cancers in males are: stomach, prostate, NHL, liver and Kaposi sarcoma



Top 5 cancers in females are: breast, cervix, stomach, ovary and NHL

Lessons learnt

During this short implementation period of Kigali Population Based Cancer Registry, there are many lessons learnt and best practices that will help to move forward with establishment of the national cancer registry. The main lessons and best practices are listed below.

- Ownership of the Government/MoH is key to sustainability of a national cancer registry
- Collaboration with different stakeholders in cancer control in the country is important for a successful implementation of the registry
- Good collaboration with data sources is necessary to have full access to cancer data

- Support of cancer registry based at health facilities
- Electronic Medical Records hold a great promise on having automated data into CanReg5
- A population cancer registry needs a long term plan with dedicated budget and staff for a smooth implementation of activities.
- Peer to peer learning and mentorship is instrumental to new cancer registries.

Challenges

- Limited funding for cancer registration activities mainly on salaries of cancer registrars
- Heavy case load; retrospective data collection from 2012.
- Incompleteness of medical records

Conclusion and recommendations for future directions

The preliminary results show a great promise in establishing KPBCR that will provide unbiased data, a solid basis for the evidence-based planning, monitoring and evaluation of cancer control program. In addition, it will be a strong foundation towards establishing a national cancer registry.

We recommend the following to different stakeholders

1. The MoH to avail enough budget covering staff salaries and operations of cancer registry
2. Partners should increase the support to the cancer registry to accompany the Ministry of Health in this noble initiative

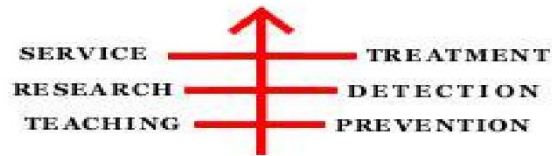
As future directions, we are planning the following:

- i. Finish retrospective data collection and initiate prospective data collection in all sites
- ii. Digital data collection (tablets, ...) to minimize the time for data entry
- iii. Explore the linkage of EMRs systems with CanReg5 for automated data collection.
- iv. Extend cancer registration activities in other health facilities from other provinces
- v. Data collection in vital statistics office.

Acknowledgements

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- Partners In Health, Rwanda
- African Cancer Registry Network
- International Agency for Research on Cancer

Tanzania



Evolution of Population Based Cancer Registries in Tanzania; A Case Study of the Dar es Salaam Registry

Introduction

Cancer is a major cause of morbidity and mortality in Tanzania and is ranked the 5th cause of death among adults (WHO, 2018). According to the 2012 census Tanzania has a population of about 55 million people with estimates of 100 new cancer cases per every 100,000 population. The forecast for 2020 is 60,000 new cancer cases per year (WHO, 2018). These are only modest estimates partly due to incomplete population statistics which makes age specific incidence rates very difficult to obtain. Furthermore, a part of the population does not access medical care and so are not recorded. The ministry of health in collaboration with implementing partners, have made efforts in enhancing information on cancer. The government of Tanzania has published plans for cancer control in the national cancer control strategy (2013- 2022). Cancer registration and surveillance falls under Goal 5 where routine and continuous collection of cancer related information and the monitoring of risk factors have been highlighted. Data management within a registry has been cited as important and has legislative support. Firstly, the ministry identifies that a fully functioning and dedicated cancer registry is a priority for cancer control service and has helped in establishing these at select facilities nationwide and some population based cancer registry (PBCR) established in 2018. Ocean road cancer institute (ORCI) has been mandated to coordinate and act as the main implementing partner. ORCI is one of the oldest health institutions in Tanzania and in 1996 by an Act (No. 2) of Parliament it was made an independent autonomous institute directly under the Ministry of Health for cancer care. ORCI offers clinics for cancer screening, treatment and palliative care and recently launched more sophisticated care for cancer care (Linear accelerator).

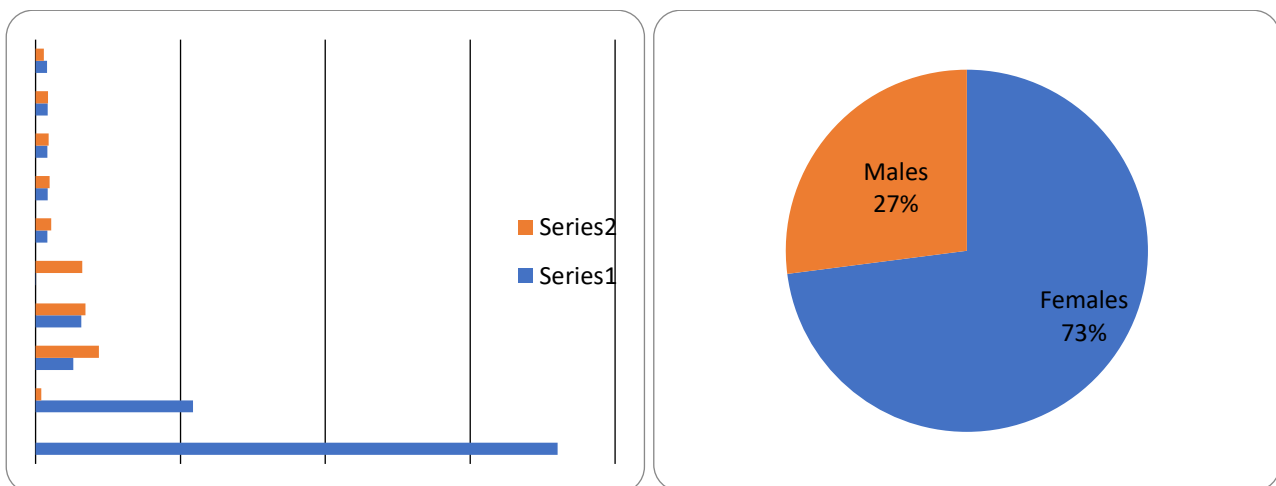
Interventions

Hospital based data and pathology-based data were the only source of cancer information in the country for a long time. This did not focus on defined populations and the absence of a centralized centre for pooling these data together compromised with accurate depictions of burden of disease in the population. The ministry of health in collaboration with implementing partners has made efforts in enhancing information on cancer. There are several population-based cancer registries though still in their infancy in Tanzania. To guide their establishment, there was development of a document outlining execution of the ministry goals, named "Strategic Implementation Plan for National Cancer Registry, Tanzania (2019 – 2022)".

There are several interventions that have been implemented such as equipping and capacitating the existing facilities within ORCI, to establish a formal cancer registry office. Office space and equipment such as desktop computers, laptops, printer/scanner, photocopier, external disk drives paved the way for implementation of the Dar es Salaam PBCR supported and funded by World Bank, AFCRN and ORCI. The Dar es Salaam population-based cancer registry is one of the registries which were established in 2018 with target population size of 5.4 Million people and geographical

coverage of 1393 sq km. Central office is located at Ocean Road Cancer Institute. This collaboration of partners has supported the staffing of the registry that currently has 1 registry supervisor and 6 volunteer registrars. The registry has recently also been joined by two epidemiologists. There has been basic training of staff, and ongoing mentorship within the African region. The staff meet weekly for discussion of registry affairs and refresher needs. The ministry of health has issued letters to all newly founded cancer registries in the country to identify their sources and prepare them for visits to collect information. For the Dar es Salaam PBCR potential sources are mandated to give ORCI authority for compilation and management of cancer information. The Dar es Salaam PBCR has mapped and engaged with their sources, including; pathology laboratories, death registries, public and private hospital medical records, hospice, diagnostic centers. The Dar es Salaam PBCR has developed a standardized data collection tool to be used across all health facilities and has trained some health care professionals from 2 of the sources. So far the Dar es Salaam PBCR has collected 3200 cases between 2017 and 2018.

Results



Best practices

- The Ministry of health has been instrumental in the building of cancer registries within the country and this is through the close involvement of partners. This is an approach modeled from the experience of our own experience with failed attempts at cancer registration. It is therefore an important lesson to advocate for registries at the ministry level and directly involve them regardless of what developmental partner has received means for conducting such projects. Ministries of health are able to declare that the sharing of cancer data be a mandatory undertaking of all relevant facilities and registries.
- Strong health care referral system for cancer in the country. Existence of well-defined sources for cancer cases/information.
- Staff that receive training provide refreshers for others within the registry. Following training of the epidemiologists, there was a trickledown effect of the knowledge through registry-wide refresher sessions. This has been successful particularly because of the ongoing mentorship with training agencies.

Challenges

- Awareness about cancer registration therefore interfering with cooperation at the institute level. This is a result of the position of the registry within the organogram of ORCI. This challenge has been presented for action and negotiations involving the ministry and ORCI are underway to provide new location and detangle it from bureaucracy. Additionally, advocacy for cancer registration within the institution is a next step.
- Lack of a unique identifier to adequately track the referral pattern of cancer patients. This is a challenge with tracing patients. The government notes this need and is strengthening identification systems via National Identification (NIDA).
- Limited utilization of electronic medical record systems by other facilities and therefore data completeness is a challenge. With mentorship at various data sources, this will be addressed.

Conclusion

The commitment from government of Tanzania and partners is evident in the implementation of the Dar es Salaam population based cancer registry all under the custodianship of ORCI. ORCI will endeavor to acquire quality cancer data in Tanzania through implementation of activities for the strategic plan for cancer control.

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- Dar es Salaam population based cancer registry information

Uganda

Can population-based cancer registries be established in rural settings? Experiences from Mayuge cancer registry

Background

Uganda has a population of over 44,270,563 with a growing burden of Non-Communicable diseases. Over 32,000 new cancer cases and 21,000 cancer related deaths occurred in 2018. Currently, 56,238 people are living with cancer¹. Late presentation, limited access to diagnosis and treatment services contribute to the high death rate due to cancer in Uganda². The five commonest cancers in Uganda are; cancer of the cervix, Kaposi sarcoma, breast cancer, cancer of the prostate and non-Hodgkin lymphoma. Among children, Lymphomas, soft tissues sarcomas, leukemia and cancer of the kidney predominate. The commonest risk factors driving the cancer burden in Uganda include; infections, physical inactivity, exposure and use of tobacco, alcohol, growth and aging³.

The government is working on a cancer control strategy to aid harmonization of cancer control efforts in the country. The strategy has 8 thematic pillars including health promotion and prevention, cancer screening and early detection, diagnosis and treatment, survivorship and rehabilitation, Palliative care, Cancer surveillance, research and Monitoring and evaluation. In regards to access to cancer care, Uganda Cancer Institute (UCI) is the only public institution that provides comprehensive cancer care services. However, there are other regional cancer centers that provide cancer treatment and prevention services such as Gulu, Mbarara, Jinja, Mayuge and Arua. These regional centers provide cancer screening, chemotherapy only as well as cancer awareness.

Uganda has both population and hospital-based cancer registration systems. The Kampala Cancer Registry is one of the oldest population based cancer registries in Africa dating back in 1951. Due to its central location and low population coverage, there was need to document the burden of cancer in other geographical areas that have significantly different risk factors and population dynamics. Two more registries were planned and established in Gulu and greater Iganga-Mayuge Districts. With the three registries in place, the current coverage is 14% of the Ugandan population. However, UCI in its 10 year strategic plan, intends to increase the coverage to 30% by revitalizing two registries one in Mbarara and another in Arua regions.

Table 1: Status of cancer Registration in Uganda

No	Name of registry	Type	Population coverage	Ownership	Year of establishment	Region	Status
1	Kampala Cancer Registry	PBCR	2629,132	Makerere University	1951	Kyadondo county (Kampala + part of Wakiso)	Running
2	Gulu Cancer Registry	PBCR	762,000	Lacor Hospital	2013	Greater Gulu	Running
3	Mayuge Cancer Registry	PBCR	2,340,312	Uganda Cancer Institute	2017	Greater Iganga-Mayuge	Running
4	Mbarara Cancer Registry*	PBCR	Unknown	-	-	Greater Mbarara	Closed
5	Kuluva*	PBCR	Unknown	-	-	Aura	Closed
6	UCI cancer registry	HBCR		UCI		Uganda	Running

*Closed due to limited financial support

Intervention

With financial and technical support from World Bank Trust Fund Regional Program for cancer registration through ECSA-HC, Mayuge cancer registry (MCR) was prioritized for strengthening. MCR is located in Eastern Uganda and has a geographical coverage of 2,340,312 people from 7 districts including; Mayuge, Iganga, Luuka, Namayingo, Bugiri, Namutumba, and Bugweri Districts. The population comprises mainly of Basoga and Bagweri cultural groups. The Uganda Cancer Institute has the mandate to oversee cancer registry activities and therefore provides the technical aspects of the project in Mayuge and works hand in hand with the local government which provides human resources and infrastructure. The major inputs include; a) Registry staff training, b) knowledge exchange workshops, c) Equipment's: ICT and Furniture.

Results

Data collection is on-going. So far we have retrospectively (2015-2017) collected 873 cases and analyzed 439 cancer case from sources within the catchment area and a few referral sites. The age-group of 30-49 years has the highest number of cases compared to other age groups.

Figure 1: Distribution of top cancers by gender in Mayuge cancer registry catchment area, 2015-2017

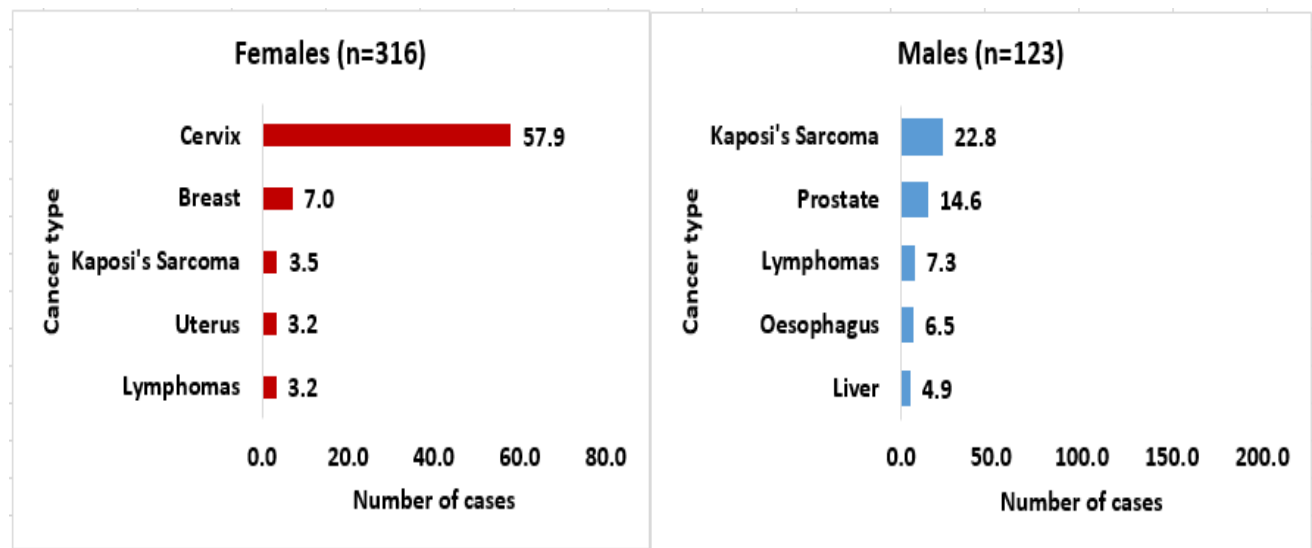
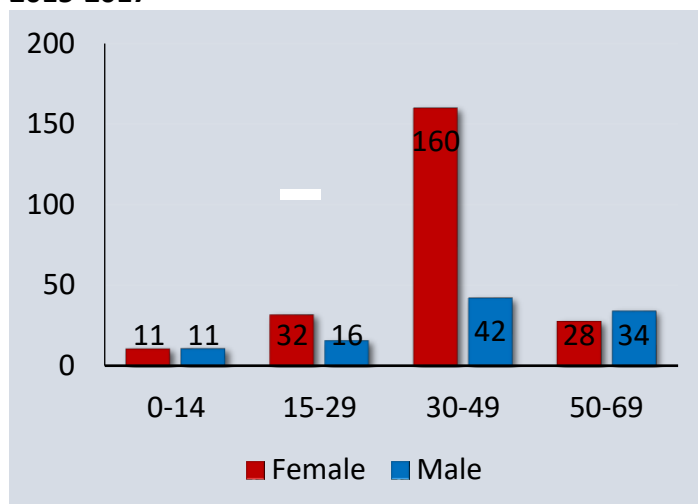


Figure 2: Distribution of top cancers by age-group in Mayuge cancer registry catchment area, 2015-2017



Best & promising practices

- Collaboration with the local government, in providing the human resources and infrastructure for cancer registration activities is a strong foundation for sustainability of the project.
- Cancer registration requires teamwork, dedication and patience to achieve data quality.
- Peer to peer mentorship is vital for knowledge exchange and networking for cancer registration.
- Integration of cancer registration into other cancer control efforts/activates promotes a sense of ownership and proper utilization of available resources.

Challenges

- Poor and unstandardized documentation practices in most facilities leading to incomplete data during registration.
- Attrition of trained human resource due to local government internal transfers

- Inadequate utilization of existing community health structures to enhance cancer registration including follow-ups.
- The targeted data collection has not been achieved due to delays in project implementation
- Limited diagnostic services within the catchment area coupled with low index of cancer suspicion among health workers.
- No system of death registration which may limit information of mortality

Conclusion and recommendation

This project has enabled Mayuge cancer registry to develop human resource capacity, acquired ICT equipment and furniture that are essential for cancer registration. In addition, the project has enhanced data collection, knowledge exchange and networking with other cancer registries cross the East African community.

Recommendation

- As we come to the end of the project life, we recommend continued support to facilitate data collection, compilation, analysis, interpretation and dissemination for decision making.
- The division of Non-Communicable Diseases within Ministry of health should adopt the community health approach into cancer control efforts.
- Uganda Cancer Institute should work with the local government to retain health workforce that are trained in cancer registration.
- The government to integrate cancer specimen referral system into the existing hub systems.

Way forward

- Continue with data collection to achieve completeness of cancer registration
- Perform further advanced analysis and documentation for comparisons with regional cancer monitoring indicators.

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