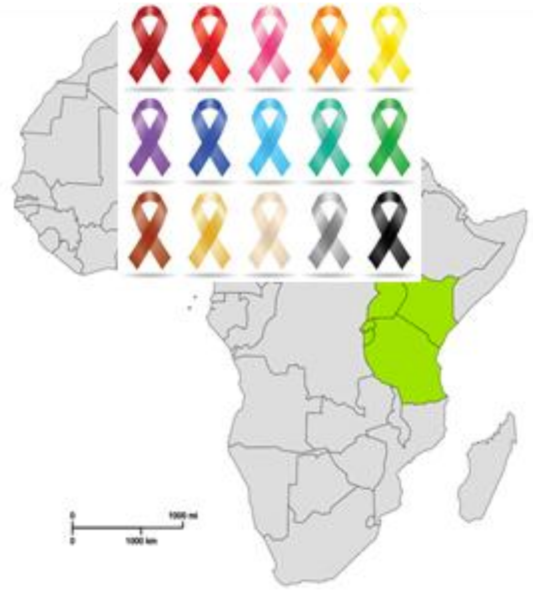
EAST, CENTRAL AND SOUTHERN AFRICA HEALTH COMMUNITY

Regional Program for Cancer Registry



Statistical Capacity Building Project for Cancer Registries in East Africa Project Status Report

user

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EAST, CENTRAL AND SOUTHERN AFRICA HEALTH COMMUNITY

Fostering Regional Cooperation For Better Health

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Introduction

Background

Non-communicable diseases —including cancer— have become more prominent in Africa over the last decade, as a result of longer life expectancy due to improved health care and changes in lifestyle. Cancer diseases constitute an enormous global health challenge; they were among the leading causes of morbidity and mortality worldwide, with approximately 14 million new cases and 8.2 million cancer related deaths in 2012[1]. The incidence and mortality are projected to rise rapidly worldwide; more than 20 million new cases of cancer are predicted in 2025, with four fifths of the burden falling on low and middle-income countries (LMICs) and by 2035, almost 15 million cancer-related deaths per year are forecasted to occur[1,2]. Reducing the cancer burden will require significant long-term investments and commitments, especially as countries plan to establish and upgrade radiotherapy and other treatment facilities.

In response to that growing global burden of cancer, in 2013, WHO launched the Global Action Plan for the Prevention and Control of Non-Communicable Diseases (NCD) 2013-2020 that aims at reducing by 25% premature mortality from cancer, cardiovascular diseases, diabetes and chronic respiratory diseases by 2025. Since then, it is obvious that NCD surveillance is critical to providing the information needed for policy and program development and to support the monitoring and evaluation of the progress made in implementing cancer and other NCDs related policies and programs.

Cancer information systems based on registries is unique and form an essential pathway to achieving goals included in the global action plan for prevention and control of cancer diseases; they are of pivotal importance not only in providing information on cancer burden but also in measuring the impact of cancer prevention and control interventions. Cancer registries are at the core of the Global Monitoring Framework on Non-communicable Diseases (NCDs), which includes a commitment to report on cancer incidence and type as an indicator for the global mortality target of reducing premature NCD deaths. Population-based cancer registries are the best option to measure and understand the cancer burden in the country by providing national estimates (a subset of the national population can be sufficient for ensuring an adequate coverage of a population-based registry).

Cancer surveillance based on population-based registries is well advanced in western world and has been shown to be the unique source of information for cancer program planning, monitoring and evaluation. However, only 1 in 5 low and middle-income countries have functional cancer registries either hospital based, or population based only covering one city or a region of the country[3] (figure 1).

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[1] World cancer report 2014;

[2] International Agency for Research on Cancer (IARC)

[3] Global Initiative for Cancer Registry Development (GICR)

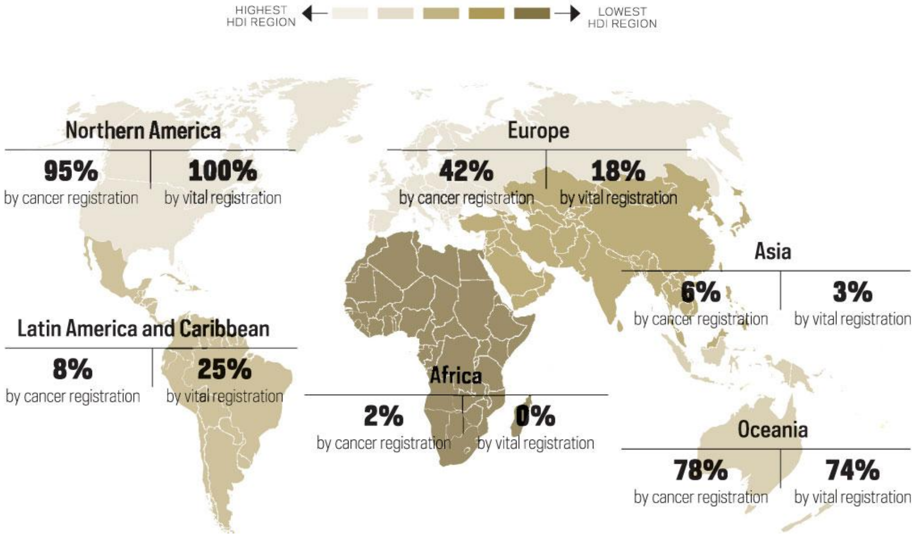


Figure 1: Proportion (%) of the regional population covered by high quality cancer registration

Population-based cancer registration is an essential component of cancer care and control programs and contributes to building national statistical capacity. Furthermore, population-based cancer registries (PBCR) provide unbiased data on cancer burden in the community and are a standard requirement for cancer control planning and evaluation in every country of the world. Additionally, cancer registration schemes are key to understanding the nature and risk factors associated with cancers. They are especially valuable in LMICs, where few other population-based data on cancer occurrence and outcome are available[4]. The need to increase capacity for cancer registries is high as they provide important statistics that would bolster efforts to:-

- Step up advocacy and resource mobilization for cancer care and control.
- Inform design of cancer prevention and control policies and programs, including cancer screening, diagnosis, treatment and palliative care.
- Strengthen awareness and encourage early screening, detection and treatment

The establishment of a cancer registry is always possible, even in low-resource settings. Improving both the numbers (to expand the population coverage) as well as the quality of population-based registries is critical for ensuring progress in cancer prevention and control interventions.

The Project Development Objective (PDO)

The Project development objective is to strengthen capacity for collecting, analyzing and sharing data on cancers in the five East Africa member states

- The project contributed to the three main pillars of Bank support towards universal health coverage. Access to timely information on the rising cancer disease burden is critical for: -
  - developing financial protection mechanisms to ensure that households are not impoverished by catastrophic health spending;
  - providing quality services in a timely manner, to promote early detection and treatment; and
  - addressing risk factors associated with cancers.

Project components

- **Component 1:** Core Capacities for Cancer registration and statistics
- **Component 2**: Statistical Capacity Building and Mentorship
- **Component 3:** Advocacy and knowledge exchange

Expected results

The expected results were: -

i. **Strengthened/Functional population-based cancer registries *(achieved)*; and**

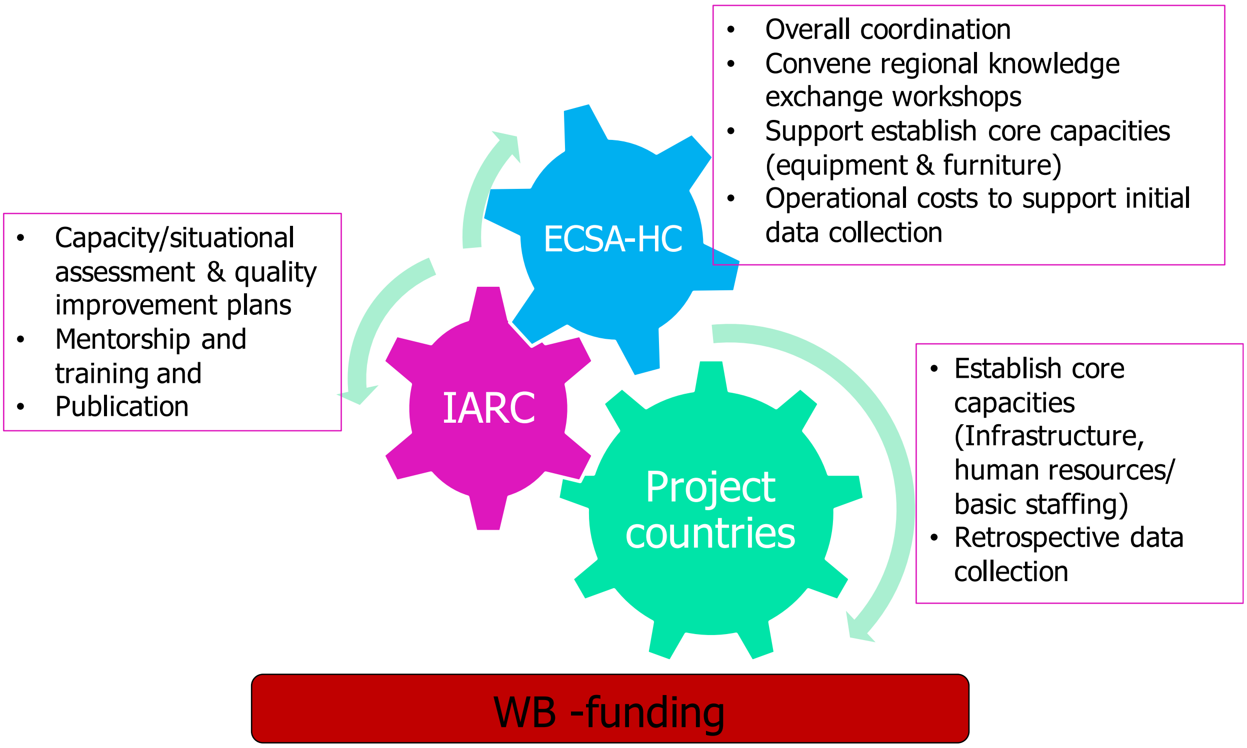
Nine new population-based cancer registries were established

- Government provided infrastructure and staff to support the registries
- Fully equipped with the hard wares and soft wares required for cancer registration
- Trained the staff to build their capacities on cancer registration and cancer data analysis for decision making
- Data abstraction conducted with retrospective data as well as prospective data abstracted to 2019.

ii. Publication of a regional compilation of cancer statistics ***(achieved).***

- Developed a case study publication with cancer statistics from the established cancer registries.

ECSA-HC worked with The International Agency for Research on Cancer (IARC), and the African Cancer Registry Network (AFCRN) to support the countries to strengthen capacity for establishment/ strengthening of population-based cancer registries. Below were the working arrangements and sharing of responsibilities between the various stakeholders.



- Overall coordination
- Convene regional knowledge exchange workshops
- Support establish core capacities (equipment & furniture)
- Operational costs to support initial data collection

- Capacity/situational assessment & quality improvement plans
- Mentorship and training and
- Publication

- Establish core capacities (Infrastructure, human resources/ basic staffing)
- Retrospective data collection

Achievements

The project development objective was achieved. The project countries established a new Population Based Cancer Registry (PBCR) each increasing from 6% to 18% before the project implementation with Burundi, Rwanda and Tanzania that initially did not have a population-based registry establishing one each. Kenya and Tanzania increased the coverage with the additional registries. In Tanzania, another partner Bloomberg supported the establishment of additional PBCR (covering a population of 4.3M; Table 1).

Table 1: Population coverage with PBCR prior and after the project initiation

Country	Country Population	Coverage by PBCR		Population covered by PBCR (current)
		Before 2016	Current (2019)	
Tanzania	59,000,000	0%*	16%	9,600,000*
Rwanda	12,000,000	0%	13%	1,500,000
Burundi	12,000,000	0%	8%	1,000,000
Kenya	47,600,000	14%	25%	11,800,000
Uganda	42,860,000	8%	16%	6,800,000
Total 5 countries	**173,460,000**	**6%**	**18%**	**30,400,000**

** No previous population-based cancer registry; ** contribution for coverage by registries set up with funding from Bloomberg (population of 4.3M)*

Component 1: Establish Core Capacities for Cancer registration and statistics

Under this component, the project was expected to carry out the following activities: -

a) Strengthen/make functional population-based cancer registries; and
b) Procure of essential ICT and office equipment to make render the registries functional
c) Provide operating costs, including installation of an open source cancer registration software (CANREG);
d) Provide Technical Assistance to establish and operationalize cancer registry and provide statistical capacity building

Through the Ministries of Health, the governments of the project countries committed to complement the efforts to operationalize and sustain the registries by providing the required infrastructure and deploy human resources to work in the established registries. The following are achievements under this component: -

Strengthen/make functional population-based cancer registries

Selection of population for registry set-up

In May 2018, ECSA-HC undertook the project initiation mission to all the project countries to discuss and agree on the coordination roles and capacity needs to strengthen/establish the new registries. During the visits, countries had an opportunity to share their updates on the burden of cancer, institutional arrangements on prevention and control of cancer and cancer registration work in the country and plans towards establishment of population-based cancer registries.

Countries identified priority areas for support and activities to be implemented under the project in line with the project objectives. Each country identified a population-based registry to be established/and or strengthened under the support of the project with a **total of 35, 275 cancer cases registered as shown in table 2 below.**

Table 2: Summary of the registries established by the end of the project

Country	New registries	Population covered	Registrations done	Previous PCBR
Burundi	Bujumbura population registry (1)	1M	602 cases	None
Kenya	National Cancer Registry County registries - Embu, Nyeri, Meru and Nakuru PCBR; (5) and Kamamega, Kitui, Bomet – Hospital based registries	Amalgamation of data from existing registries, New county based PCBR and cancer treatment centres – 9.3M	12,272	Nairobi, Eldoret, Kisumu
Rwanda	Kigali Population registry (1)	1.5 Million	14,124	Hospital based
Tanzania	Dar es Salaam Population registry (1)	5.3 Million	7207	Hospital based
Uganda	Mayuge Population registry (1)	2.3 Million	1070	Gulu Kampala
Total			**35,275**	

- **Burundi**: **Bujumbura City Population Based Cancer registry *(New)*** to cover a population of 1,053,099 inhabitants which is close to 10% of the country's population estimated at 11,680,080 as of 2019. The registry is hosted at the Ministry of Health and Fight Against AIDs, Department of Non-Communicable Diseases. The registry registered **602 cases ICD-10 codes C00-C95) covering a period of three years from 2016-201**8. The main data sources of information on cancer cases were: -

  A. Hospitals
  - Kamenge Teaching and Referral Hospital
  - Kamenge Military Hospital
  - Hopital Prince Regent Charles
  - Clinique Prince Louis Rwagasore
  - KIRA Hospital
  - Private clinics and Nursing homes

B. Laboratories

- Bujapath
- Kamenge Teaching and Referral Hospital Histopathology laboratory

- **Kenya**: **National Cancer registry** ***(New)*** covering the cancer statistics from the already established population-based registries in Nairobi and Eldoret; and nine Cancer treatment centers and registries located in Bomet, Nakuru, Nyeri, Kisumu, Meru, Kitui, Embu, Garissa and Kakamega counties as well as Kenyatta National Hospital (KNH). Four of the county's treatment centres were developed into population-based cancer registries using funds from this project. These were Nyeri PBCR ***(New)***- covering a population of 759,164 people; Embu PBCR ***(New)*** – covering 608,599 people; Meru PBCR ***(New)***- covering 1,545,714 people and Nakuru PBCR **(New)-** covering 2,162,202 people. The National Cancer registry captured **12,292 cancer cases (7940, 64.6%, females)** by the end of the project covering a period of 2016 (in the county registries and earlier in KNH) to June 2019 among females (Table 3).

Table 3: Registries established in Kenya through the project support

County	Registry	Population covered	Cancer cases registered by the end of the project
National	Kenya National Cancer Registry		
Nyeri	Nyeri PBCR	759,164	2,000
Embu	Embu PBCR	608,599	1,122
Meru	PBCR	1,545,714	635
Nakuru	PBCR	2,162,202	1,900
KNH	KNH hospital registry		10,000

- **Rwanda: Kigali Population Based Registry** ***(New)*** **covering** Kigali capital with estimated population of 1.5 million people. The data are collected from all health facilities and institutions in the City of Kigali where cancer cases can be found, these include district hospitals, private clinics, hospices and laboratories as well as vital statistics from the births and deaths registration bureaus. The project supported the abstraction of cancer cases from the Kigali population (but also from other regions) from July 2018 after training. The registry recorded **14,124** cases covering a period of 2015 to June 2019 and making the total of **19,936** cases as of 25th December 2019 including 5,812 cases collected from a previous period through a registry that covered a period of 2007 to 2014. The former cancer registry that was collecting data from the major 4 referral hospitals and 2 district hospitals collected data September 2007 to October 2014 had registered **5,812** cancer cases before collapsing in 2014 as it was not mainstreamed into the government programs.

- **Tanzania: Dar es Salaam Population Based registry** ***(New)*** covering Dar es Salaam region with a population of about 5.3 million people. The Dar-es-salaam Cancer Registry is housed at the Ocean Road Cancer Institute (ORCI) which is specialized Centre for cancer care in Tanzania. Between 2015 and 2018, **7,207 cases of cancers were registered: 2,220 among men and 4,987 among women**.

- **Uganda: Mayuge Population Based Cancer Registry** ***(New)*** covering Eastern part of Uganda with estimated population of 2.3 million from 6 districts of the Eastern Uganda. Mayuge registry experiences has informed the establishment of other four-regional cancer population-based registries that are in the plan for Uganda. Between 2015 and 2017, **1,070 cases of cancers were registered in Mayuge registry, 355 men and 715 women.**

Provision of infrastructure for the new Population Based Cancer registries

The Ministries of Health of the five project countries have worked with the Cancer Institutes/Programs to allocate the office space for the established/ strengthened PBCR. In ***Tanzania,*** the Dar es Salaam registry is housed at the Ocean Road Cancer Institute, while Kigali PBCR is housed at the Rwanda Biomedical Centre (RBC) in Kigali. The Mayuge registry is based at the **Cancer Unit within the Kigandalo Health Centre and is also technically supported by the Uganda Cancer Institute (UCI) until fully established.** The Kenya National Cancer Registry is housed at the Ministry of Health, within the National Public Health Laboratory campus (Afya Annex). In Kenya and Burundi, the registries are located in the Ministry of Health premises.

Physical facility of Mayuge Registry at Kigandalo Health Centre

Placement of Human resources to support the PBCR

The project countries committed to allocate staff to work in the established population-based cancer registries and cater for their salaries as part of the bigger plans of implementing cancer surveillance work under the respective National Cancer Control plans. All the five countries have dedicated project focal person and staff working on established PBCRs.

In Uganda, the Mayuge Cancer registry has **one full time staff** (cancer registrar) supported by technical persons (registrars) based at UCI on voluntary basis to collect data in the health facilities and within Kampala and UCI for the population coming from Mayuge region (in order to clean up duplicates). The recruitment processes are underway to recruit two additional staff, one Epidemiologist and one Cancer Registrar to support the timely data collection and analysis.

Rwanda- Rwanda Biomedical Centre (RBC) has created a cancer registry coordination team and an office at RBC. The team composed of **two cancer registrars,** cancer unit staff, **NCDs epidemiology officer** and one additional staff from another division. RBC also engaged five volunteers to support data collection activities for a period of 6 months, the project supported their allowances for a period of 3 months. The team is in charge coordinating registration activities, do active data collection in health facilities, manage the central cancer registry data base, provide regular training/ mentorship/supervision/ data quality assessment to facilities.

Tanzania- the Ocean Road Cancer Institute where the Dar es Salaam registry is based has used internal mechanisms to address the human resources requirements for the cancer registry. Currently they are using available human resources; 3 permanent professional medical recorders and 5 support team to support the cancer registry work.

Kenya- the National Cancer Registry is using a team of health information officers responsible for health data to undertake the cancer registration tasks. The team is working closely with the Pathologists and the Oncology laboratory at the National Public Health Laboratory Services and registrars from the eight cancer treatment centers mentioned above. The head of Cancer Program at the Ministry of Health provides coordination of the registry work with two technical officers and three volunteers.

Burundi- Burundi has allocated 5 staff to work in Bujumbura registry and they are all under government payroll. The Director of NCDs is responsible for providing oversight to the established Bujumbura Cancer Registry and four other staff from the Oncology unit have been assigned the responsibility of running the activities of the Bujumbura, registry.

The personnel assigned to the registry work in all countries have received training in Basic cancer registry techniques to equip them with the necessary skills for cancer data abstraction, cleaning, entry in CanReg and data analysis.

Procurement of ICT equipment and furniture for the cancer registries

The project supported all the five countries to procure ICT and office equipment, including computers (i.e. desktops, laptops, i-pads), printers and scanners and related equipment and supplies to facilitate cancer data collection, analysis and reporting. Registry office furniture has also been procured to enable operationalization of the registries. The project countries have also been supported with the funds to cover for operating costs such as provision of internet services (internet modems) where needed and other key inputs (e.g. office supplies, logistical support) and installation of an open source cancer registration software (CANREG). Procurement of items to enhance capacity to build the registries and facilitate cancer data collection was successfully concluded.

Table 4: ICT and office equipment procured to support the established cancer registries

No	Country	List of procured equipment
1	Burundi	4 desktop computers, 3 laptops, 2 photocopiers, 4 stabilizers, 2 External disk drive, 1 printer
2	Kenya	6 Desktop computers, 3 Laptops, 10 Tablets, 10 External hard disk drive, 2 Printer/copier, 3 desktop internet link, 2 Filing cabinets, 3 office Desks, 7 office chair and 120 rims of photocopying papers
3	Rwanda	4 desktop computers, 4 laptops, 2 UPS, 2 Printers, 1 projector, 4 internet router, 2 external disk drive, 4 office chairs, 4 office desks, 6 filing cabinet, 1 server, 5 wireless cards, 5 modem and other office supplies
4	Tanzania	8 desktop computers, 2 laptops, 8 UPS,4 I-pads, 1 printer/scanner, 6 office chairs, 6 office tables, 4 filing cabinets, 1 internet router, 6 external disk drives and other office supplies
5	Uganda	2 desktop computers, 3 laptops, 1 printer/copier, 2 I-pads, 1 office cupboard

Component 2: Statistical Capacity Building and Mentorship

This component aimed to enhance the capacity of the cancer registry team on cancer registry data collection, analyzing (statistical skills) and reporting through basic and advanced (intermediate) registry training, mentorship by seasoned cancer registry experts and south to south learning through knowledge exchange visits in established registries. Below are the activities planned under this component: -

a) Technical training on basic and advanced cancer registration
b) Adoption of standardized instruction manuals for cancer registrars and data collection forms in order to facilitate statistical analysis and comparison across registries within and across countries
c) Workshops to network cancer registry experts from participating countries with counterparts in other countries and with regional and global experts
d) Mentorship support for cancer registries by international cancer experts/registrars
e) South to South knowledge exchange/peer learning and mentorship with teams from counterpart cancer registries on learning missions

One hundred and thirty-two experts were trained through various capacity building and mentorship programs organized in the region.

Training and capacity building

Basic cancer registry training and adoption of standard instruction manual: ECSA-HC in collaboration with the in-country experts (from the existing cancer registries) organized and facilitated basic training on cancer registration in Burundi, Kenya and Uganda. A total of **82 health record officers (cancer registrars) were trained on basic cancer registration; Burundi (20), Kenya (24), Rwanda (24) and Uganda (14)**. The training comprised of both theoretical and practical sessions on data entry/management using CanReg5 software. Tanzania cancer registrars were trained with the support from another partner.

The training comprised of topics data sources for cancer registration, Cancer surveillance tools, ethical considerations in cancer registration, measures for data confidentiality, use and release of registry data, data abstraction, coding in cancer registration, international classification of diseases for oncology (ICD-O), CanReg5: installation, use and management, data quality in cancer registration, cancer surveillance sites in each country among others. The training also involved adoption of standardized instruction manual/data collection tools to be applied used for data collection. The theoretical sessions were coupled with practical skills on abstraction of data and coding in cancer registration and data entry in CanReg5. Abstracted data from the different sources was used to fill the abstraction forms and used to test for completeness, validity and % morphological verification.

Advanced (intermediate) level training: In October 2018, IARC and AFCRN organized a training on data analysis in Entebbe, Uganda in conjunction with the Annual Review meeting of the AFRCN. A total of **10 participants were trained; Kenya (2); Tanzania (3); Uganda (4) and Burundi (1).** The topics were mainly on data presentation, combining analyses skills and production of reports. The IARC team has also developed technical material for local staff on capacity building activities. A set of draft slides for an on-line learning module entitled, ‘Planning and Management of a Population-based Cancer Registry’ have been completed. The learning objectives are to: review key Population-based Cancer Registry (PBCR) concepts; understand the key components in planning of a PBCR; define criteria to select the target population; describe profiles and roles of cancer registry staff; understand the key components in management of a PBCR; and explain the role of advisory committee and describe the main stakeholders involved. A narrative script has been developed to assist regional trainers in using the material and to guide the next steps in forming a short instructional video. A set of standardized slides have been completed on two topics: CanReg; and Coding and Staging.

Participants and facilitators during the basic training on Cancer Registry in Kenya and Uganda

Mentorship support for cancer registries by international cancer experts/registrars

The Cancer Registry mentorship program was organized by IARC and AFRCN to provide more personalized training on cancer registry management. It was designed for purposes of mentoring cancer registry managers and directors to have more in-depth knowledge on how to run a population-based cancer registry and how to analyse and generate various reports from registry data. 8 participants from 4 project countries (Tanzania, Uganda, Kenya and Rwanda) participated in the mentorship program which was held at the Nairobi Cancer Registry in Kenya for four countries in February 2019.

Workshop on cancer registry data analysis, presentation and report writing

The team of **28 participants** from the five project countries participated on a workshop on data analysis, presentation and report writing conducted back to back with the closing meeting. The workshop was facilitated by an experienced cancer registrar from Eldoret Cancer Registry. Participants were trained on data analysis and data quality indicators and later on they used their respective countries data to analyze and generate cancer registry reports from CanReg5.

Table 4: Staff trained in basic, advanced and mentorship capacity building programs

Country	Basic training	Intermediate level training	Data quality improvement, analysis and reporting	Mentorship support
Burundi	20	1	3	• 4 participants supported to Eldoret cancer registry for learning exchange visit • Hosted mentorship program for 8 participants (Tanzania, Rwanda, Burundi, Kenya) • Kenya national team provided mentorship to registrar in the various county registries (57 participants in various county registries)
Kenya	24	2	10	
Rwanda	24		2	
Tanzania	0	3	4	
Uganda	14	4	5	
ECSA-HC			4	
Total	82	10	28	70

South to South knowledge exchange

The project supported four (4) staff involved in the cancer registration from Burundi (Bujumbura) and Uganda (Mayuge) for a knowledge/learning exchange visit to the Eldoret (Kenya) Cancer Population Based Registry. The exchange visit was meant to improve further the capacities of the registrars and improve quality of cancer registry data. The visit included: **-**

- Field cancer cases abstraction (data sources from hospitals, vital registration centres)
- Data entry in CanReg system
- Data cleaning and generation of reporting

The cancer registry team from Uganda and Burundi during the knowledge exchange visit in Eldoret Cancer Registry at the AMPATH Oncology center

The team from Burundi received on-site mentorship support from a cancer registry expert from KEMRI. The support was mainly on data quality improvement, data entry, cleaning and analysis and how to effectively use CanReg5 software. The mentorship support was very essential given that the team had minimum experience working in cancer registry.

Data collection and registration of cancer cases

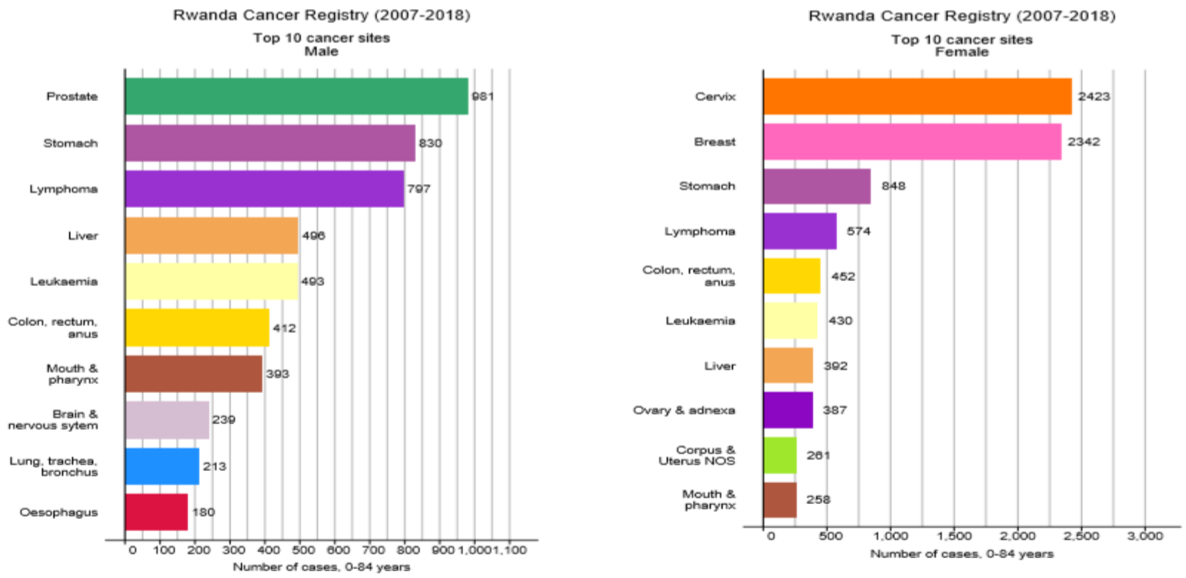
The project has provided support to facilitate costs of data collection activities in established registries. The data collection is done from public and private hospitals, hospices and births & deaths registration bureaus. Data are collected retrospectively (covering data from current period to about 3-5 years back) done in a period of about 10 months. Due to delay in start-up, some countries like Burundi began data collection in February 2019 due to limited experiences in setting up a registry. The setup was completed in all countries, staff trained and data collection undertaken. Funds have been disbursed to all five countries and the data collection activities have been initiated following training of the cancer registrars. As earlier indicated, 35,275 cancer cases were abstracted and registered in CanReg broken down.

Rwanda- Overall **19,936** cancer cases are in the cancer registry database by December 25, 2019 when the project closed (with 5812 cases in the former database and 14,124 cases in the current registry started from July 2018. Retrospective data collection status is estimated to be around 95% by the project closure. Retrospective data collection has been finished in all public hospitals within cancer registry coverage including the University Teaching Hospitals located in the City of Kigali (Rwanda Military Hospital (RMH), Kigali University Teaching Hospital (CHUK), and King Faisal Hospital (KFH), District Hospitals (Kacyiru, Masaka, Kibagabaga and Muhima), Hospices, other facilities out of Kigali managing many residents from the City of Kigali such as Butaro Cancer Center of excellence (BCCOE), Butare University Teaching Hospital (CHUB), Rwinkwavu hospital and Kabgayi Hospital Ophthalmology unit. These hospitals have updated data collected up to December 2018 and are the main source of information of Kigali cancer registry.

Cancer data abstraction has continued using government funds to reach 100% and proceed with prospective data. The registry proceeded to collect data from 12 Private clinics in Kigali (with 3-5 % cases the registry) and mortality data in Medical Certification for Cause of Death (MCCOD) at the MoH and birth and deaths registration by the National Institute of Statistics of Rwanda (NISR).

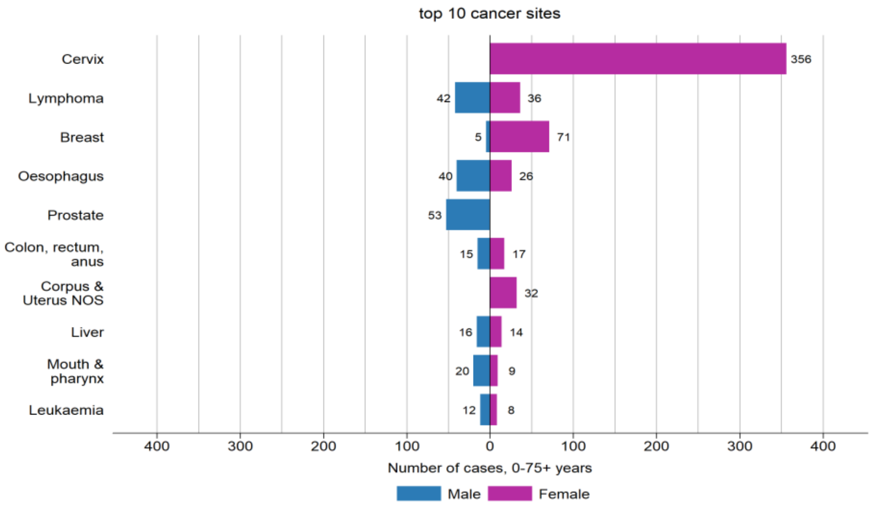
From the initial analysis on the data collected, the cancers recorded in men were prostate (981 cases), stomach (830 cases) and lymphomas (797 cases) while in female, cervical cancer (2423 cases) and breast cancer (2342 cases) topped the list.

Figure 2: Top ten cancers recorded in the Kigali cancer registry



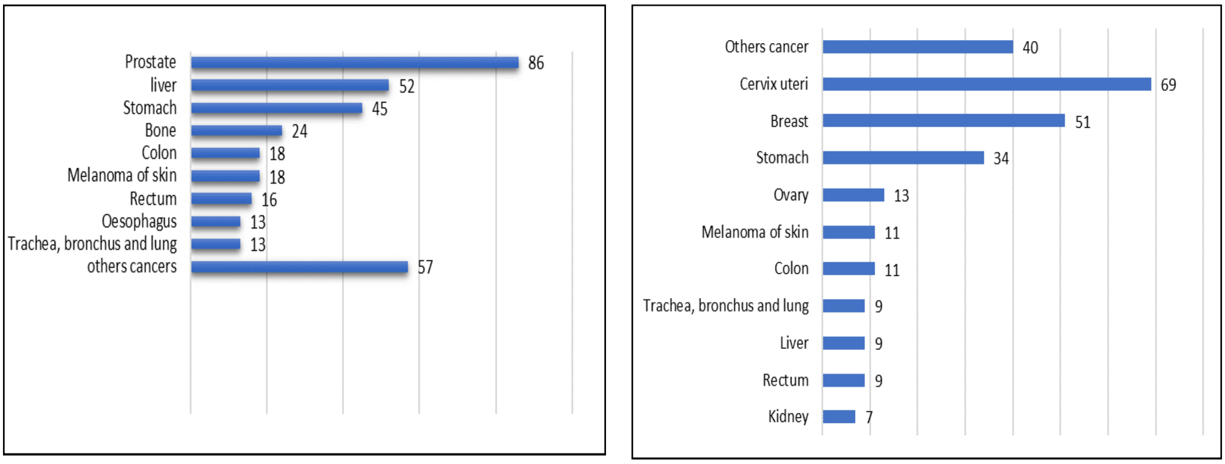
Uganda- the data collection for Mayuge registry started in January 2019. Data for the Mayuge registry are collected from the health care facilities within the catchment area referral sites in the capital that where cancer patients from Mayuge can receive medical attention such as national/cancer treatment centers, pathology laboratories as well as palliative centers (a total of 10 sites). A total of 1,070 cases were abstracted and registered in CanReg by December 2019 from patient records from the mentioned sites. In men, prostate cancer cases were the most commonly diagnosed malignancy (53 cases), followed by lymphoma (42 cases) and esophagus cancer (40 cases). In women, cervical cancer was the most commonly diagnosed malignancy (356 cases), followed by breast (71 cases).

Figure 3: Top ten cancers recorded in the Mayuge cancer registry



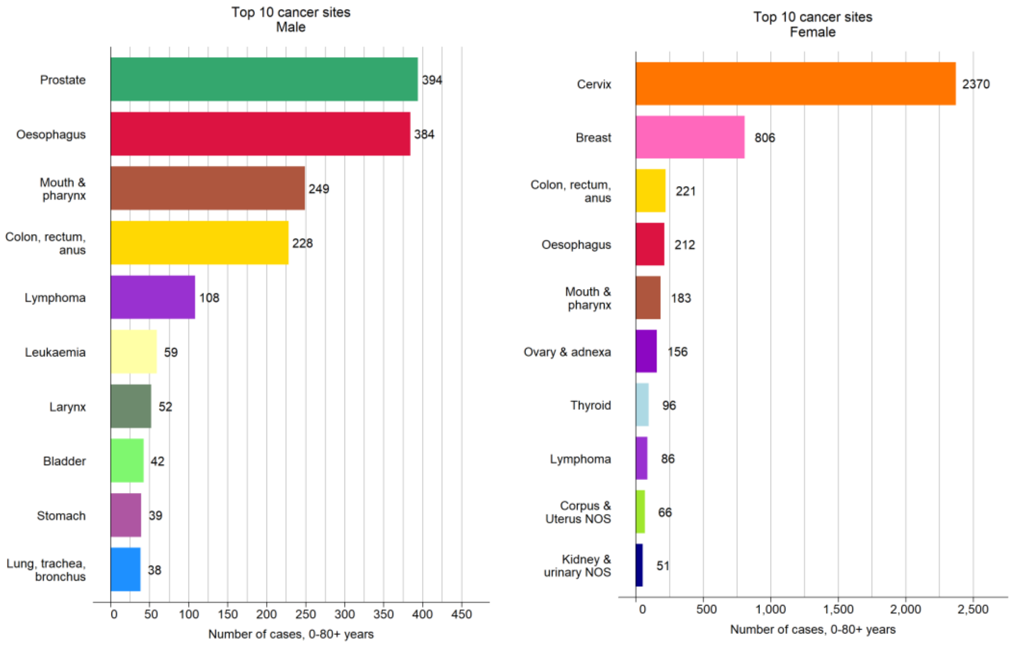
Burundi- The data collection activities started in February 2019 covering following a stakeholder's consultation meeting with representatives from hospitals (public and private) in Bujumbura to sensitize them on the cancer registry work and seek support. Data was collected for three-year period (2016-2018) with 602 new cancer cases (ICD-10 codes C00-C95) registered in the Bujumbura cancer registry. Of these, 43% (263/602) were females. For males, the leading cancer types were, prostate (86 cases), liver cancer (52 cases) and stomach cancer (45 cases). In females, cancer of uterus (69 cases), breast cancer (51 cases) and stomach cancer were the most common.

Figure 4: Top ten cancers recorded in Bujumbura cancer registry



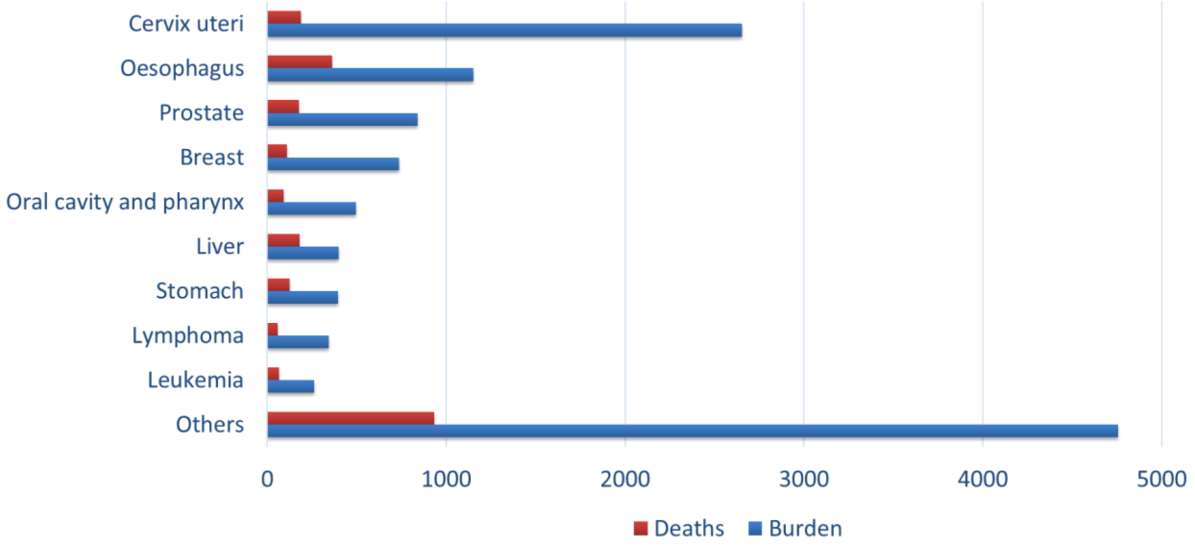
Tanzania- Data collection has commenced from ORCI and other 11 facilities in Dar es salaam. The process of finding cancer cases and abstracting was started from the August 2018, the source of cases were from clinical setting, diagnostic as well as treatment facilities in Dar-es-salaam. The process involved case finding, data abstraction, data entry, coding and quality management. A total of 7205 Cases were abstracted and entered in the CanReg data base by December 2019. In males, prostate and oesophagus were the most commonly diagnosed malignancies with 394 and 384 cases, followed by mouth & pharynx (249 cases). In female, cervical cancer was the most commonly diagnosed malignancy with 2,370 cases, followed by breast cancer (806 cases).

Figure 5: Top ten cancers recorded in Bujumbura cancer registry



Kenya: Data collection activities started in October 2018 from the 7 cancer treatment centers. From the data abstraction and consolidation at the National Registry in Kenya, a total of 12,292 cases were recorded at the KNCR from various counties. The top cancers are Cervical/Uterine & Breast in females and Prostrate & Oesophagus. In males, prostate and oesophagus cancers were the most commonly diagnosed malignancies, while in female, cervical and breast cancers were registered in higher numbers.

Figure 6: Top ten cancers recorded in Bujumbura cancer registry



CanReg enhancement and mobile CanReg5

IARC have developed a new analytic function for CanReg5, which is free, open source software for cancer registries. A series of statistical programs have been written in 'R' to automate the production of standard outputs. These include data quality reports (modelled on those used at IARC in its publication, Cancer Incidence in Five Continents), descriptive epidemiology (tables and graphics that present analyses by characteristics of person, place and time) and annual registry reports (based on a standardized report developed with the AFRCN using the Kampala Cancer Registry in Uganda). An enhanced feature has the ability to have registries customize their data queries and easily modify the output. Users can select various formats for graphics, such as saving them as MS PowerPoint slides and PDF files. A proof of concept for CanReg5 as a mobile data collection has been completed and plan to undertake field testing is underway.

Component 3: Advocacy and knowledge exchange

Networking workshops

In order to enhance knowledge and experience sharing, the project organized a workshop in September 2017 in Nairobi, Kenya bringing together experts from existing cancer registries, ministries of health, statistical offices and technical partners and institutions, including CDC, AFRCN among other stakeholders to share experiences in setting up and operating cancer registries. This information was critical to enable countries with no established population-based registries to providing to support implementing countries. The meeting discussed the modalities of implementation of the project to strengthen population-based cancer registries in the Partner States; shared experiences on the current status of the cancer registries in the respective countries highlighting key achievements, lessons and challenges faced by the registries; discussed the project work plan and the implementation road map and linkages with ongoing work to strengthen oncology services in the countries and fostered partnerships with key stakeholders to collaborate in the implementation. Following the implementation of the project over the period, a follow up workshop is scheduled for the April 2019 when the countries will share the findings of the data collection and prepare preliminary reports/case studies from the available data and use the opportunity for further advocacy on the need for the governments to invest in cancer registration activities.

Video/conference exchange calls:

The project has been facilitating discussions through video/conference calls to enable countries to review the progress jointly, share challenges and offer suggestions to improve the implementation and address the challenges experienced in the data collection process.

Support countries to analyse cancer data, write up the case studies

ECSA-HC organized a regional meeting in April 2019 which participants from all 5 project countries participated. The key objective was documentation of case studies was to improve awareness and understanding of cancer registries works. Each country was given an opportunity to develop case studies depending on the level of information they have and present the case study for peer review between countries. The developed case studies were finalized and it was agreed that each country will use them to develop abstracts for the AORTIC Cancer Conference to be held later in the year as part of dissemination.

Regional Project Close Out Meeting and Dissemination Meeting

ECSA-HC organized a regional project close out meeting which brought together 36 participants from all the 5 (five) project countries. Participants were representatives working in the established cancer registries, members of NCDs TWG under EAPHLN project, the East Africa Cancer Registries project (supported by the Africa Development Bank, AfDB) and other regional and global experts. Country delegates had an opportunity to share overview of cancer burden, prevention and control strategies and updates of cancer registry work in their respective countries. The overall performance of the project was also presented together with key lessons, challenges and opportunities. A significant shift was noted on the coverage of population by increased number of population-based cancer registries from less than 10% in 2016 to 18% population coverage in 2019. Country teams had an opportunity to identify priority areas related to cancer prevention and control and cancer registries, which requires further support at country and regional level. The project further

Indicators	Unit of Measure	Baseline	Cumulative target	Cumulative achievement	Comments
PDO Level Results Indicators					
Population based cancer registries established	Number	**0**	**3**	**9**	**Over-achieved -** (Bujumbura cancer registry-Burundi; Kigali cancer registry-Rwanda; Mayuge cancer registry - Uganda; Ocean Road Cancer Institute registry - Tanzania; in Kenya – KNCR, Meru county registry, Embu County registry; Nakuru county registry)
Cancer registries equipped and installed with essential hardware's and software	Number	**0**	**5**	**7**	**Over-achieved** (two additional registries have been equipped in Kenya)
Number of staff trained in cancer registration and statistical analysis of cancer data	Number	**0**	**30**	**120**	**Over-achieved**
Intermediate Result indicators					
Annual publication of a regional compilation of cancer statistics	Number	**0**	**1**	5	5 abstracts were prepared and shared during the AOTIC Conference in Maputo, Mozambique
Regional case study with country specific case information prepared and disseminated	Number	**0**	**1**	5	5 case studies have been prepared; more data is being analyzed to enrich the case studies
Number of cancer registries that have adopted standardized instruction manual for cancer registration	Number	**2**	**5**	9	**Achieved** (IARC standard collection tool and instruction manual adopted during the basic training)
Development of GIS system for cancer registry information	Number	**0**	**5**	Not completed	Planned to be completed after data analysis is completed.
Number of staff mentored on cancer registration and cancer statistics analysis and use	Number	**0**	**50**	**57**	**Achieved**

Summary of performance

The project had eight indicators, three PDO level indicators and five intermediate results indicators. All the three PDO indicators have been achieved while four of the five intermediate indicators have been achieved. Only the GIS mapping indicated was not concluded as the data collection was done to the last month. The data would then be used to map different cancers occurring in different places. A detailed results framework is hereto attached as Annex 1 and a summary provided below.

Summary of results framework: The project has achieved the targets set for all the three PDO indicators; this is equivalent to 100 percent and four out of five Intermediate Outcome Indicators, equivalent to 80 percent. The overall performance is 88 percent.

Disbursement and Financial reporting

The project budget was US$499,980 which was fully disbursed by the end of the project which represent 100% disbursement rate.

ECSA-HC Prepared and submitted quarterly Interim Financial Reports for the project throughout the project period timely. These quarterly reports were reviewed by the Senior Financial Management Specialist and were given clean bill. The expenses were documented in the World Bank client connection system after receiving no objection from the project Task Team Leader. The expenditure as at 31st March, 2020 was US$498,837 which represent 99.8% expenditure rate against the budget. The detailed financial performance based on project activities and categories is shown below.

Summary of financial performance

Activity	Total (budget)	Cumulative Expenditure March 2020	Variance	Spent % age
Conduct the capacity assessments of cancer registries to determine current status and needs in five East Africa Partner states	38,115	33,900	4,215	89%
Section I: Total	**$38,115**	**33,900**	**$4,215**	**89%**
Activity II (a) procurement of essential ICT and office equipment	81,665	108,715	(27,050)	133%
Activity II (b) Operating costs; provision of internet services, where not available; and other key inputs (e.g. office supplies, **logistical support for data collection**);	87,000	73,258	13,742	84%
Activity II (c) Provide Technical Assistance to establish and operationalizing cancer registry and provide statistical capacity building	44,000	53,293	(9,293)	121%
Section II: Total	**$212,665**	**$235,266**	**($22,601)**	**110%**
Activity III (a): adoption of standardized instruction manuals for cancer registrars and data collection forms	42,150	41,810	340	99%
Activity III (b): technical training on basic and advanced cancer registration	51,480	61,964	(10,484)	120%
Activity III (c): Workshops to network cancer registry experts from participating countries with counterparts in other countries and with regional and global experts	56,555	56,772	(219)	100%

Activity III (d): Mentorship support for cancer registries by international cancer experts/registrars	26,700	27,120	(420)	102%
Activity III (e): South to South knowledge exchange/peer learning and mentorship with teams from counterpart cancer registries on learning missions	17,640	6,822	10,818	39%
Activity III: Total	**$194,525**	**194,488**	**$35**	**100%**
Activity IV (a): consultancy services to support countries to analyse cancer data, write up the case studies and develop the GIS	14,100	1,092	13,008	8%
Activity IV (b): workshops with key stakeholders to disseminate findings and generate support for scaling up cancer registries and cancer statistics capacity building	40,575	34,091	6,484	84%
Activity IV: Total	**$54,675**	**$35,183**	**$19,492**	**64%**
Grand Totals	**$499,980**	**$498,837**	**$1,141**	**99.8%**

Category	**Budget**	**Cumulative Expenditure March 2020**	**Variance**	**Spend Variance (percentage)**
Goods (max 20% of grant)	81,665	104,785	(23,120)	128%
Services	233,555	199,945	33,610	86%
Training/Capacity building and workshops	144,185	155,864	(11,679)	108%
Other workshops	40,575	38,243	2,332	94%
Total Cost	**$499,980**	**$498,837**	**$1,143**	**99.8%**

Key challenges and lessons:

- Cancer registration is integrated into all cancer control activities or programs within the countries although the coverage for the cancer surveillance that includes ***cancer registration with population-based cancer registries is still low***. The project however, contributed to expanding the coverage and through advocacy countries have realized the need to support cancer registration.

- Data abstraction has been a challenge due to ***poor documentation practices at some health facilities*** such as patient files and laboratory records with incomplete information and this was partially mitigated by onsite training/support and mentorship at the affected health facilities.

- Registries that are not located within the main capital cities (Kenya treatment centres and Mayuge registry) are affected by ***limited cancer diagnostic services*** within catchment area. The registrars needed to compare the data from the capital cities in order to minimize duplicates and clean the data that is eventually logged into the respective registries for the particular population.

- Cancer data quality is not a one-time event but rather a continuous process. The registry maintains data quality by rigorously reviewing all the information abstracted and verified by the coordinator before they are entered into CANREG.

- The project had a delayed start up and considering that some of the countries were setting up new registries that never existed, it took some time for the registries to set up, nominate staff and commence data abstraction. The registration took off well with over 35,000 cancer cases registered by the end of the period. Data analysed and countries produced reports that would be useful for the cancer programs. Countries still continue with the data collection post the project.

Recommendations and next steps

- ECSA-HC will continue to facilitate knowledge sharing and interaction among the countries and engage more stakeholders to sustain the gains.

- ECSA-HC will continue to advocate for the member states to continue investing human and financial resources to scale up and sustain the cancer registry work and continue to invest in cancer diagnosis/pathology services that is critical to enhance the quality of data from the established registries.

Annex 1: Detailed Results Framework

PDO Level Results Indicators*	**Core**	**Unit of Measure**	**Baseline**	**TARGET YEAR 1 (2018)**	**ACHIEVED YEAR 1 (2018)**	**TARGET YEAR 2 (2019)**	**ACHIEVED YEAR 2 (2019)**	**Comments**
Indicator One: Population based cancer registries established	☐	Number	0	1	1	3	9	New Population based registries have been set up/established in prioritized regions in each of the countries with the required infrastructure, human resources and equipment (National population-based cancer registry in Kenya, other population-based cancer registries have been established in Embu, Nyeri, Meru and Nakuru. Bujumbura registry in Burundi, Dar es Salaam registry in Tanzania, and Kigali registry in Rwanda and Mayunge in the Eastern part of Uganda. Cancer registration in these registries is continuing post the project timeline using the set foundation and government resources.
Indicator Two: Cancer registries equipped and installed with essential hardware's and software	☐	Number	0	0	1	5	7	Population based cancer registry in Burundi, Rwanda, Kenya, Tanzania and Uganda has been equipped with - 3 Desktop computers, 2 Laptops, 10 Tablets, 1 Printer/copier, 2 Filing cabinets, 2 office Desks, 3 office chair and stationaries. (Two more registries in Kenya have been equipped)
Indicator Three: Number of staff trained in cancer registration and statistical analysis of cancer data	☐	Number	0	15	38	30	82	At total of 82 Staff have been trained on basic cancer registration - Burundi (20), Kenya (24); Rwanda (24) and Uganda (14). A total of 10 participants were trained in advanced cancer registration; Kenya (2); Tanzania (3); Uganda (4) and Burundi (1) (on cancer registration software, data analysis and dissemination of cancer registry information). 10 participants were trained by IARC in advanced cancer registry in October 2018. In December 2019 a total of 28 staff were trained in data analysis and report writing. Cumulatively for year 1 and year 2 a total of 120 personnel has been trained.
	INTERMEDIATE RESULTS							
	Intermediate Result (Component One):							

Intermediate Result indicator One: Annual publication of a regional compilation of cancer statistics	☐	Number	0	1	NA	2	5	5 abstracts were prepared and shared during the AOTIC Conference in held in November 2019 in Maputo, Mozambique.
Intermediate Result indicator Two: Regional case study with country specific case information prepared and disseminated	☐	Number	0	0	NA	1	5	5 case studies have been developed, will be enriched after the ongoing data analysis exercise is completed
Intermediate Result indicator three: Number of cancer registries that have adopted standardized instruction manual for cancer registration	☐	Number	2	3	3	5	9	IARC standard collection tool and instruction manual adopted during the basic training) All the nine established registries have been installed with and are using standardized software CanReg5
Intermediate Result indicator four: Development of GIS system for cancer registry information	☐	Number	0	1	NA	5		Work in progress to develop a GIS system, to be finalized after the data analysis has been completed
Intermediate Result indicator five: Number of staff mentored on cancer registration and cancer statistics analysis and use	☐	Number	0	35	30	53	57	Mentorship conducted Kenya where Staff have been mentored in Embu, Nyeri, Meru and Bomet Counties. Four participants from Burundi and Uganda were supported for an exchange visit to Eldoret Registry