

**PROJECT INFORMATION DOCUMENT (PID)
IDENTIFICATION/CONCEPT STAGE**

Report No.: PIDC107068

Project Name	Regional Program of Cancer Registries
Region	AFRICA
Country	Africa
Lending Instrument	IPF
Project ID	P163187
Borrower Name	Ministry of Health, Community Development, Gender, Elderly and Children
Implementing Agency	East Central and Southern Africa Health Community
Environment Category	C - Not Required
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Initiation Note Review Decision	The review did authorize the preparation to continue

I. Introduction and Context

Country Context

The East African Community member states have demonstrated commitment to strengthening the availability and utilization of quality data to address the needs of the post-2015 Millennium Development Goal Agenda. All five countries (Burundi, Kenya, Rwanda, Tanzania and Uganda) recognize that the availability of quality data underpins effective policy making, planning and program implementation. National Statistical Offices are committed to work with line ministries to develop capacities to address emerging needs, such as the proposed 25 percent reduction in premature mortality from non-communicable diseases (NCDs) by 2025.

All countries have made progress in developing national statistical strategies but coverage and capacity remain highly variable. For example, the 2014-2018 National Strategy for the Development of Statistics of Rwanda (NSDS2) acknowledges the importance of working with key sectors, including health, to strengthen the availability, quality and utilization of data to track progress towards the country's Economic Development and Poverty Reduction Strategy. The EDPS has identified four thematic areas, fourteen priority sector strategies (including health), and seven cross cutting issues (including NCDs). Uganda also has a strong tradition of strategic planning for statistical development. The Ministry of Health (MOH) is an integral part of the National Statistical System (NSS) and one of the most important producers of official statistics. Uganda launched its first five-year Plan for National Statistical Development aimed at strengthening not only the Uganda Bureau of Statistics (UBOS) but also the NSS, including the statistical capacity of the MOH. The 2013-2018 Enhancing Quality and Usability of Statistics Plan aims to tackle gaps in data collection, and analysis; and in human and physical statistical infrastructure.

While all EAC member states have made good progress on strengthening health information systems, reporting on NCDs is incomplete and unreliable. There are large inequities in coverage and quality of cancer registration globally with limited information currently available in resource-limited settings like in East Africa. According to the African Cancer Registry Network, only 22 member states out of the 54 African sovereign states have registries that contribute to its database, but not all meet required standards and most represent a small proportion of the population . National Statistical Offices have an important role to play in brokering partnerships and supporting Ministries of Health. Collaboration between National Statistical Offices and Ministries of Health would tap local expertise, and strengthen prospects for sustainability.

Sectoral and Institutional Context

Many countries in sub-Saharan Africa are facing a dual burden of disease with an unfinished communicable disease agenda, and the rapid emergence of chronic diseases. This double burden of disease places increasing demands on fragile health systems, contributes to escalating health care costs, and generates staggering economic losses and premature deaths. Reducing these multiple burdens will require averting or delaying the onset of NCDs, and preparing for the consequences of population aging.

NCDs are projected to rise rapidly in the next 5-10 years and will represent a growing share of the burden of disease and premature death in low and middle-income countries. In sub-Saharan Africa, NCDs will reach roughly 40 percent of the burden of disease by 2030 due to changes in lifestyles, increasing urbanization, and aging populations. By 2030, deaths from chronic diseases will outstrip those from infectious diseases. Tracking and monitoring the emergence of NCDs will be critical to guiding the design of public health interventions and minimizing loss of human life that can undermine economic growth. Ministries of Health need to bolster their statistical capacity to systematically collect, analyze, and utilize data on NCDs.

Seventy percent of cancer deaths occur in low-and middle-income countries, which are often poorly prepared to deal with the growing burden of cancer. According to the latest Global Burden of Disease, sub-Saharan Africa had about 850,000 new cancer cases and roughly 600,000 deaths in 2012. Cancer rates will double in sub-Saharan Africa by 2020. The NCD Global Monitoring Framework includes monitoring of cancer incidence, underscoring the importance of establishing mechanisms for this purpose (World Health Assembly, 2013).

Population-based cancer registration is an essential component of cancer care and control programs and contributes to building national statistical capacity. Cancer registration schemes are key to understanding the nature and risk factors associated with cancers, to inform planning of health services, resource allocation, and policy formulation . Cancer registries in rural areas provide insights as to whether these groups face different risk factors and patterns of disease. Globally, quality data from cancer registries has been instrumental in shaping policies and informing resource allocation decisions. The need to increase capacity for cancer registries is high. Cancer registries will 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.

Several important regional and global initiatives and institutions are building capacity for cancer

surveillance in sub-Saharan Africa. These initiatives are critical to ensuring that countries adopt standardized indicators in accordance with international standards. They also facilitate cross country benchmarking, tracking and performance monitoring. The African Cancer Registry Network (AFCRN) aims to improve the effectiveness of cancer surveillance, a fundamental part of a strong cancer control program, by conducting expert evaluations and providing technical support. The AFCRN has succeeded in expanding the activities of the East African Cancer Registry Network.

The United States Centers for Disease Control and Prevention (CDC) has a long standing relationship with the majority of the EAC member states and is now giving priority to cancer registration. In 2010, the Division of Cancer Prevention and Control began to expand its global partnerships to improve cancer registration in low- and middle-income countries. The Office of International Cancer Control was recently established to lead global health initiatives, including improving the availability of high-quality cancer registries and surveillance data. CDC is a global partner of both the Global Initiative for Cancer Registration and the World Bank.

The East, Central and Southern Africa Health Community has a mandate to support regional health initiatives and has established a close working relationship with the five countries, providing technical support, coordinating training, and facilitating cross country learning. In the context of the Bank-funded East Africa Public Health Laboratory Networking Project, ECSA-HC is currently coordinating the design and implementation of country pilots that aim to establish pathology services at project-supported laboratories. The cancer registry initiative dovetails well with the pathology pilots getting underway as the number of patients diagnosed with cancer will rise and require systematic tracking. ECSA-HC can organize joint training, facilitate the dissemination of harmonized statistics, and advocate for greater resources.

Relationship to CAS/CPS/CPF

All five countries are committed to improving the health and welfare of their populations, with the CAS/CPF making explicit reference to this goal as part of the emerging SDG agenda. Most strategies also acknowledge the importance of having strong statistical capacity to monitor and track progress towards the SDGs with a view to fostering evidence-based policymaking. Some countries are receiving support to strengthen broad statistical capacity (i.e. Kenya Statistics Program for Results; Uganda Statistical Capacity Building; Africa Centers of Excellence Project in Rwanda).

II. Project Development Objective(s)

Proposed Development Objective(s)

The Project Development Objective (PDO) is to strengthen capacity for collecting, analyzing and sharing data on cancers in the five East Africa member states.

Key Results

The main results expected would include: (i) number of operating population based cancer registries ; and (ii) publication of a regional compilation of cancer statistics. A draft Results Framework is included in Annex I.

III. Preliminary Description

Concept Description

The project will generate important evidence on how cancer registries can play a key role in tracking

the emergence of a major public health problem in sub-Saharan Africa, and contribute to strengthening the capacity of Ministries of Health to produce reliable cancer statistics based on population based registries. While the focus of this initiative is on cancers, the project will generate valuable information for monitoring and tracking other NCDs. With support of the statistical trust fund, the EAC member states have an opportunity to serve as a model for other countries in sub-Saharan Africa that are facing similar challenges. Working together, in collaboration with key technical partners (i.e., AFCRN, CDC) under the leadership of ECSA-HC that has a sound track record of coordinating regional initiatives, will foster economies of scale and catalyze adoption of best practices.

Building linkages between statistical work and cancer registration

In order to develop strategies to effectively manage, control and reduce the rapidly growing cancer burden in the five EAC member states, collection of high-quality data is of paramount importance. This project proposes a three stage process for building statistical capacity for the collection, analysis and use of cancer statistics, namely: (i) data collection ➤(cancer registries play a pivotal role in collecting statistics on new cases, and case fatality rates, broken down by gender, age and geographic location from hospitals, clinics, laboratories, radiology departments, pathology centres, and vital statistics departments through direct reporting by these sites or through active case finding by registry staff; strengthening the capacity of the five countries to generate high quality, complete and accurate statistics on cancer will be critical as the majority do not have well established population cancer registries; (ii) data analysis and statistical capacity building ➤(once the data is collected and compiled it will be important to conduct analyses to better understand risk factors, disease staging, and other parameters; to this end, it will be important to strengthen the statistical capacity of the cancer registries to enable them to produce high quality cancer statistics; the proposal proposes to build capacity by providing critical equipment (hardware and software) and by conducting training of registrars, enumerators and statistical experts; and (iii) utilization of statistics - information generated through the statistical analysis of cancer data will inform policymaking by providing data on the disease burden, epidemiology, types of cancer and other important information. The figure below depicts the linkage between cancer registries as the data generation sources, the statistical aspects and use of statistics for decision making.

In order to build statistical capacity and generate quality cancer data, the project will support four key activities (Figure 1):

- ⇒(§ Conducting country assessments to identify strategic locations for establishing additional cancer registries.
- ⇒(§ Establishing core capacity at new sites, by procuring basic equipment (i.e. computers, printers, and office furniture)
- ⇒(§ Providing training, capacity building and mentorship for cancer registrars, statisticians and other key personnel.
- ⇒(§ Disseminating findings from cancer registration pilots, documenting the value added of this approach to strengthen national statistical capacity, providing a platform for data sharing for use by researchers and exploring ways to consolidate and scale up results.

A. Country Assessments: ECSA-HC will coordinate the country assessments, with support of ANCR and CDC, and in collaboration with respective Ministries of Health, National Statistical

Offices and other local actors. The goal of the assessments would be to build on existing initiatives supported by other partners (as described in Annex II) by identifying priority locations for additional cancer registries in Kenya, Rwanda, Tanzania and Uganda, and for setting up the first cancer registry in Burundi. The assessment team would use standardized internationally recognized questionnaires and would organize focus group discussions and/or interviews with key stakeholders. ECSA-HC has successfully coordinated similar country assessments and is well placed to lead this effort.

B. Core Capacity: The governments will agree on the pilot sites, provide appropriate office space, and deploy personnel to the cancer registers. The trust fund will support the following complementary activities: (i) procurement of essential information and communications technology (ICT) and office equipment, including computers (i.e. desktops, laptops, i-pads), printers and scanners, not to exceed 20 percent of the total grant; and (ii) operating costs, including installation of an open source cancer registration software (CANREG); provision of internet services, where not available; and other key inputs (e.g. office supplies, logistical support). The trust fund will also support recruitment of local consultants, on a selective basis and as strictly needed, to get the initiative underway more quickly.

C. Training, Capacity Building and Mentorship: Given that the quality of cancer registry data is highly dependent on the skills, and qualifications of staff this component is critical to the overall success of this initiative. To this end, the project will fund: (i) adoption of standardized instruction manuals for cancer registrars and data collection forms; (ii) technical training on basic and advanced cancer registration (e.g. abstracting and coding practices, statistical analysis, interpretation and presentation of cancer data/information, and preparation of reports) and on CANREG; (iii) mentorship visits by regional and international experts; (iv) sensitization on cancer registration and the role of staff in the registry operations to ensure uptake; (v) peer visits to facilitate cross country learning. The trust fund will support: (i) training and workshop costs; (ii) consulting services (including travel); and (iii) operating costs (including travel).

D. Dissemination and Advocacy: In order to improve awareness and understanding of the importance of cancer registries, country specific case studies will be prepared, documenting achievements, and proposing future directions. The case studies will play a key role in building broad-based ownership and in exploring ways to institutionalize cancer registries in collaboration with National Statistical Offices. The dissemination activities will involve providers, medical records personnel, community leaders and patient groups, to generate broad based support. In order to understand the spatial patterns of cancer and to generate information on risk factors, a geographic information system (GIS) will be piloted. The fund will support: (i) consultancy services to write up the case studies and develop the GIS; and (ii) workshops with stakeholders to disseminate findings and generate support for scaling up.

Figure 1: Strengthening Cancer Registration in East Africa

B. Implementing Agency Information

ECSA-HC will be coordinating the implementation of the project in collaboration with technical partners (e.g. CDC, AFCRN). ECSA-HC brings more than 40 years of experience within the region, working with member states and other stakeholders to further the goal of better health outcomes. ECSA-HC has a solid track record of coordinating similar initiatives, collaborating with governments to build capacity, mobilize regional and international expertise, share best practices, and advocate for improved policies. The organization has developed a unique set of competencies

relevant to this project, as described in Annex III.

Project Stakeholder Information

Cooperating Organizations

In each country, ECSA-HC will bring together experts from existing cancer registries, ministries of health, statistical offices and technical partners and institutions (e.g. ACRN, CDC, United States National Cancer Institute, NCI/NIH, and the College of Pathologists of East Central and Southern Africa, COPECSA).

⇒(§ In Kenya, the two established population based registries, (i.e. Eldoret Registry located at the Moi Teaching and Referral Hospital and the Nairobi Cancer Registry located at the Kenya Medical Research Institute, KEMRI) are important partners to support capacity building based on the knowledge and experience gained to date.

⇒(§ In Rwanda, ECSA-HC will work with the University Hospital of Butare, which manages a hospital based cancer registry, and with the Butaro Cancer Center of Excellence, which provides a full spectrum of cancer care and treatment.

⇒(§ In Tanzania, ECSA-HC will partner with the Ocean Road Cancer Institute (ORCI), an independent autonomous institute directly under the Ministry of Health; and with the Muhimbili University of Health and Allied Sciences which have pulled forces to roll out a cancer/pathology program at the University.

⇒(§ In Uganda, the team will work with the Uganda Cancer Institute that manages one of the strongest population based cancer register programs on the continent, Makerere University that hosts the Kampala cancer registry, and St. Mary's Hospital Lacor that hosts the Gulu cancer registry.

⇒(§ Finally, in Burundi, that has no established cancer registry, ECSA-HC will be guided by the discussions initiated between the Ministry of Health, and the Centre Hospitalaire Universitaire de Kamenge (CHUK).

Annex IV includes responses to the TFSCB Specific Questions.

IV. Safeguard Policies that Might Apply

Safeguard Policies Triggered by the Project	Yes	No	TBD
Environmental Assessment OP/BP 4.01		x	
Natural Habitats OP/BP 4.04		x	
Forests OP/BP 4.36		x	
Pest Management OP 4.09		x	
Physical Cultural Resources OP/BP 4.11		x	
Indigenous Peoples OP/BP 4.10		x	
Involuntary Resettlement OP/BP 4.12		x	
Safety of Dams OP/BP 4.37		x	

Projects on International Waterways OP/BP 7.50		x	
Projects in Disputed Areas OP/BP 7.60		x	

V. Financing (*in USD Million*)

Total Project Cost:	0.49998	Total Bank Financing:	0
Financing Gap:	0		
Financing Source			Amount
Trust Fund for Statistical Capacity Building			0.49998

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