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Cost of Operating Population-Based Cancer Registries: Results from 4 Sub-Saharan African Countries

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Abstract

Large differences exist in the coverage and quality of cancer surveillance systems across the world, with limited data currently available from low-resource settings. Information on the resources required to register cancer cases are needed in order for global, national, regional, and local stakeholders to adequately support cancer registry operations. The objective of this study is to estimate the cost of cancer registration and report the cost per cancer incident case, the cost per inhabitant in the area covered by the registry, and cost allocated to specific registry activities. The International Registry Costing Tool (IntRegCosting Tool) of the Centers for Disease Control and Prevention was used to assess the costs and resources used by 4 registries in sub-Saharan Africa (Zimbabwe, Uganda, Kenya, and Seychelles). The cost of registering a cancer case ranged from \$9 to \$96, with lower costs in low- and middle-income countries than in the high-income country. The cost of cancer registration at the population level is very low, ranging from 1 to 17 cents per person. The detailed cost information provided in this manuscript can help registries in sub-Saharan Africa understand the cost of their registry operations and identify approaches to improve efficiency to meet program priorities. Furthermore, it provides additional evidence to inform funding and resource allocation decisions to advance cancer registration in the region.

Keywords

African Cancer Registry Network; cancer registry; cost; economics; sub-Saharan Africa

Background

Cancer is a major public health problem in developing countries. In 2012, 57% (8 million) of the world's new cancer cases and 65% (5.3 million) of the cancer deaths occurred in the less developed countries.¹ Cancer accounts for a large proportion of health care spending, and patients often experience catastrophic expenditures and face significant barriers to treating cancer in limited-resource settings.²⁻⁵ Information from population-based cancer registries can be used to monitor the burden of cancer, develop cancer control strategies, evaluate successes of cancer screening and treatment programs, and design cost-effective interventions.⁶⁻⁸

Unfortunately, large inequalities exist in the coverage and quality of cancer surveillance systems across the world, with limited data currently available in the limited-resource setting.⁹ For example, the percentage of the population covered by cancer registries that meet the quality standards for inclusion in global statistics (*Cancer Incidence in Five Continents*, or CI5) is less than 10% in Asia, Central America, and South America, and approximately 2% in Africa.^{8,10} To address these inequalities, the International Agency for Research on Cancer (IARC), a specialized agency of World Health Organization, launched the Global Initiative for Cancer Registry Development (GICR) in 2011.¹¹ The main goal of GICR is to increase global capacity for cancer registration via establishment of 6 regional resource centers or hubs to provide technical support and guidance for strengthening the ability to collect, analyze, and disseminate cancer data by population-based cancer registries.

One of the 6 hubs is the African Cancer Registry Network (AFCRN). IARC, within its framework for the GICR, partners with the AFCRN to improve the quality of cancer surveillance in sub-Saharan Africa by: (1) providing technical and scientific support to countries; (2) delivering tailored training in population-based cancer registration and use of data; (3) promoting cancer registration in the region and facilitating associations and networks of cancer registries; and (4) coordinating international research projects and disseminating findings. The AFCRN currently has 30 members from 23 sub-Saharan African countries. One of the AFCRN membership eligibility criteria is achievement of at least 50% coverage of the target population, and increasing coverage to least 70% within 3 years of joining the AFCRN.¹²

Information on the resources required to register cancer cases is needed in order for global, national, regional, and local stakeholders to adequately support cancer registry operations. Although 2 prior studies have reported on the cost of cancer registration in sub-Saharan Africa,^{13,14} there has been no systematic assessment of the value of resources required for specific registry activities across multiple sub-Saharan African countries. One of these studies assessed funding of cancer registration in sub-Saharan Africa¹³ and reported US \$8 to \$9 to register a cancer case in 2013. This study underestimated the true cost of registering a cancer case, as in-kind contributions, value of donated services, and overhead costs were not included. The other study reported the true cost of cancer registry operations from only 2 population-based cancer registries in East Africa (US \$15.62 to register a cancer case in Nairobi over 2012 to 2014 and US \$10.22 to register a cancer case in Kampala during

2014)¹⁴ and the extent to which the findings are generalizable to other registries in Africa is not clear.

The objective of this study is to estimate the cost of cancer registration in Africa, including the cost per cancer incident case, the cost per inhabitant in the area covered by the registry, and cost allocated to specific registry activities. Our study will provide the evidence base on the total resources required to sustain registry operations and allow for comparative assessments of registry operations across registries to identify approaches to improve efficiencies.

Methods

The International Registry Costing Tool (IntRegCosting Tool) from the Centers for Disease Control and Prevention, described previously,¹⁵ was used to assess the costs and resources used by African cancer registries. This Web-based costing tool builds on a prior Excel-based tool and was pilot tested in 10 registries in Asia, Africa, the Caribbean, and South America. Lessons learned from these prior rounds of pilot testing were incorporated in developing the Web version of the costing tool.^{15,16} A convenience sample of 4 population-based cancer registries from sub-Saharan African countries was selected to complete the Web-based IntRegCosting Tool. The selected AFCRN registries vary in terms of their number of years of operation, geographic location in sub-Saharan Africa, organizational structure (eg, integral part of ministry of health), income category, geographic area covered, and case volume. The 4 registries included in this study are the Nairobi Cancer Registry (in Kenya), Kampala Cancer Registry (in Uganda), the Seychelles National Cancer Registry, and the Zimbabwe National Cancer Registry (which incorporates data from population-based registries in Harare and Bulawayo, as well as data from hospitals elsewhere in the country).

The cancer registries all participated in an introductory webinar to ensure consistency between the registries in understanding the components of the costing tool. The registries received usernames and passwords to access their registry's Web-based costing tool account. Information on costs and resources used, along with registry characteristics, was entered into 10 data modules across the Web tool. Data modules included registry background information such as funding sources, data collection approach, registry personnel, personnel activities, other personnel (such as consultants); computers, travel, training and other materials; software licensing; overhead or indirect costs; and narrative feedback. Registries received a user's guide and ongoing technical assistance during the data collection phase. The user guide included detailed definitions that described each cancer registry activity and provided examples. Each module in the Web tool had a series of embedded data quality checks in order to ensure accurate and consistent entries. For example, we ensured that date fields contained numbers that were within specified ranges. Once all pages were validated, the tool's built-in data analytic procedures automatically assessed the consistency across modules in terms of data entry (for instance, expenditures could not be more than the total of external funding and host contributions). The tool automatically summarized the results and produced a series of reports. Registries were able to review their summary reports to ensure the accuracy of the costing information.

Reports included the distribution of registry resources by budget category, distribution by source, distribution by cancer registry activity, cost per case, and cost per inhabitant. Cost data were reported for 2015 for Kampala, Zimbabwe, and Seychelles, and 2013 for Nairobi. Cancer incident cases were reported for 2 years prior to the year that cost data were reported, and correspond to 2013 for Kampala, Zimbabwe, and Seychelles, and 2011 for Nairobi. This approach was performed because cases are often processed over several years, which delays the reporting of complete cases and is consistent with methods used to calculate cost-per-case information for US cancer registries.^{16,17} After registries reviewed and confirmed their data inputs, researchers also reviewed the data to ensure that the information was entered correctly on each screen, and to confirm that results did not drastically differ for registries that participated in prior rounds. We show the descriptive statistics and costing results of the participating African cancer registries based on data collected in the IntRegCosting Tool.

Results

Table 1 presents key characteristics of participating African registries in terms of coverage, case volume, and registry data collection methods. Table 1 shows that there is substantial variation by registry in nearly every characteristic collected, including country income category, structure, and coverage. Seychelles is the newest registry, with just 9 years of operation, compared to the registry in Kampala, which has been in operation for approximately 63 years. Seychelles and Zimbabwe national registries are based out of health departments, while Kampala is based out of a public university, and Nairobi out of the Kenya Medical Research Institute. As the Zimbabwe National Registry covers the entire country, the registry has the highest population coverage (about 13,061,239), followed by Nairobi (3,400,000), Kampala (2,700,000), and Seychelles (96,858). Zimbabwe also covers the largest area (about 390,757 km²) compared to Seychelles, which has the smallest geographic coverage (459 km²).

Zimbabwe had the highest number of incident cancer cases, with 6,548 cases in 2013, followed by Nairobi (2,099), Kampala (1,735), and Seychelles (172). Kenya is the only country out of the 4 where cancer is a notifiable disease by legislation; however, this is not actively enforced. All 4 registries meet the quality thresholds necessary for inclusion in CI5. Seychelles has 10 data sources, and since the district health centers are used as referral centers, most cases are sent to the main hospital for confirmation of diagnosis. These sources include the island's hospitals, health information/statistic unit private clinics, hospice, laboratory, death certificate source, along with an oncology unit. Nairobi has 24 total sources that report cancer cases to the registry, followed by Zimbabwe with 23 sources and Kampala with 11 sources. All registries except Nairobi perform some level of follow-up to identify status of cancer patients after treatment. All registries except Kampala perform death clearance. Overall, the Zimbabwe registry has the most sources of funding ($n = 5$), while the remaining registries each have 2 sources.

The distribution of registries' resources by budget category is presented in Figure 1. There are significant differences in the distribution of each registry's resources. Both Nairobi and Zimbabwe allocate the majority of their resources towards the registry personnel budget category (60% and 55%, respectively), while Kampala and Seychelles both allocate much

smaller portions towards personnel than their other budget categories (22% and 37%, respectively). Kampala's largest budget category is toward indirect resources (overhead costs), which takes 36% of all resources and includes specific components such as rent and utilities. Seychelles' largest budget category is for computers, travel, training, and other materials, which take 40% of all registry resources.

Figure 2 shows the distribution of registry resources by core activities, those which are the primary duties performed by the registry. Out of Kampala's core registry activities, 61% of registry resources went toward data collection and abstraction; 16% toward data entry, validation, and consolidation; 16% toward database management and reporting; and 7% toward quality control. Zimbabwe National Registry had a higher proportion of registry core activities' resources allocated to data collection and abstraction (68%); followed by data entry, validation, and consolidation (28%); database management and reporting (3%); and quality control (1%). In contrast, Nairobi Cancer Registry had 25% of registry resources go toward data collection and abstraction. Nairobi's highest cost core activity was data entry, validation, and consolidation, in which 49% of resources were allocated. About 16% of Nairobi's core resources went toward database management and reporting, and 10% went toward quality control. Seychelles National Cancer Registry had a majority of its resources for core registry activities go towards data collection and abstraction (34%), followed by data entry, validation, and consolidation (29%); database management and reporting (23%); quality control (8%); and death certificate clearance (7%).

Registries' cost per case by budget category, total cost per case, and total cost per inhabitant are shown in Table 2. The Seychelles National Cancer Registry, the lone registry studied from a high-income country, has the highest cost per case and inhabitant. The registry costs about \$96 per cancer case and about \$0.17 per inhabitant in the registry coverage area. The Nairobi Cancer Registry, from a lower-middle income country, has a cost per case of about \$33 and a cost per inhabitant of \$0.02. The Zimbabwe National Registry, from a low-income country, had a cost per case of a little over \$10, and a cost per inhabitant of less than \$0.01. The Kampala Cancer Registry had the lowest cost per cancer case, about \$9, and a cost per inhabitant of \$0.01.

Discussion

Our study provides evidence that there is variation in the cost of operating population-based cancer registries in sub-Saharan Africa. The cost of processing a cancer case and cost per person in the geographic area the registry serves was lower in low- and middle-income countries (Uganda, Zimbabwe and Kenya) compared to the high-income country (Seychelles). Recent studies of economic evaluation of cancer registries report similar findings.^{16,18} In the analysis of factors affecting cost of operating cancer registries in the United States, case volume, quality of cancer incidence data, and size of area served were main drivers of cost per case registered.¹⁶

An earlier study summarized findings from qualitative interviews on additional factors that could influence the cost of registry operations.¹⁵ These factors include funding cycle (continuous in-country funding vs intermittent external funding), and organizational

structure (cancer registries embedded in larger institution such as hospital or university), volume of cases, number of reporting sources, size of area served and presence of rural areas, cost of living, number and type of data elements collected, staff turnover and training requirements, method of case finding (active vs passive), method of data abstractions (generally using paper forms rather than electronic devices), work mix (core data collection versus research activities), quality of data from reporting facilities, data exchange, reporting of nonresidence cases, annual renewal of agreements for data collection, and cancer incidence reporting mandated by law.

Some of these factors are internal to registry operations and can therefore be modified by registry management. For instance, measures can be taken toward attracting and retaining qualified staff. This may, in the long run, increase registry operational efficiencies and reduce cost.¹⁵ Other features external to registry operations, such as size of area served and distance to data sources, are beyond the control of registry management and could explain variation in cost. One factor that may account for the lower cost per case in Zimbabwe is that data collection is through passive notification from hospitals nationwide, with the exceptions of Harare and Bulawayo, which both perform active data collection. This allows the registry to collect a larger volume of cancer cases throughout the entire country, potentially achieving some economies of scale.

Another major finding is that, for cost of cancer registration at the population level, variation across the registries is very low, with a maximum cost of less than one-fifth of US \$1 per person in the geographic area the registry serves. This is similar to findings from a recently completed analysis of cost of cancer registration in low-, lower-middle-, and upper-middle-income countries.¹⁴ Seventeen cents (US \$0.17) is a small investment per capita compared to the gains from use of cancer registry data to inform comprehensive cancer control efforts—prevention, early detection and treatment—that could lead to reduction in health and financial burden from cancer.

Though this study provides information on the true cost of cancer registry operation in sub-Saharan Africa, it has some limitations. First, our sample is small, consisting of only 4 registries in sub-Saharan Africa (members of the AFCRN). Although the registries were selected to be representative, the sample is not large enough to capture all potential differences among sub-Saharan African registries. Thus, the findings from this study may not be generalizable to all registries in the region or registries that belong to the AFCRN. A second limitation of the data analysis presented in this study is that the registries reported their cost data and activities performed retrospectively. Retrospective cost data collection may lead to potential recall bias, as exact costs depended on registries' quality of record keeping and the activity-based costs depended on staff's ability to accurately estimate the portion of their time they spent on various registry activities over a period of time. Inaccuracies in the cost data were minimized through registries' use of accounting records to extract specific costs incurred. A third limitation is the diversity of the registries. Although the costs were converted from local currencies to US dollars to allow for comparison across registries, differences in cost across registries may still remain. A fourth limitation is reporting information about cancer cases that involve data collection for each case that may occur over multiple years. Therefore, there may be a mismatch in aligning registry cost to

the specific cases reported because of a lag in the reporting of cancer cases. A fifth limitation is that registry funding (especially external funding) may vary from year to year, thus the 1-year estimate provided in this study may not be an accurate estimate of the long-run trend in true cost of registry operation. A sixth limitation is that registries receive support from numerous source (including in-kind/donated contributions) and are embedded within large institutions, making it difficult to accurately estimate the total value of resources required to run cancer registries. It is therefore possible that the current analysis does not accurately estimate the true cost of cancer registry operation.

The detailed cost information—total, cost per case, cost per inhabitant, cost by budget categories, cost by core registry activities—provided in this manuscript can help registries in sub-Saharan Africa understand the cost of their operations and identify approaches to improve efficiency to meet program priorities. This information will be especially useful as Nairobi is expanding into a national registry, and Uganda is working to establish 2 new population-based registries. The new and expanded registries can leverage the experiences and lessons learned from previous cancer registration operations to develop synergies and to maintain an efficient collection of cancer cases in the growing regions. Additionally, the cost results provide additional evidence to inform funding and resource allocation decisions to advance cancer registration in the region.

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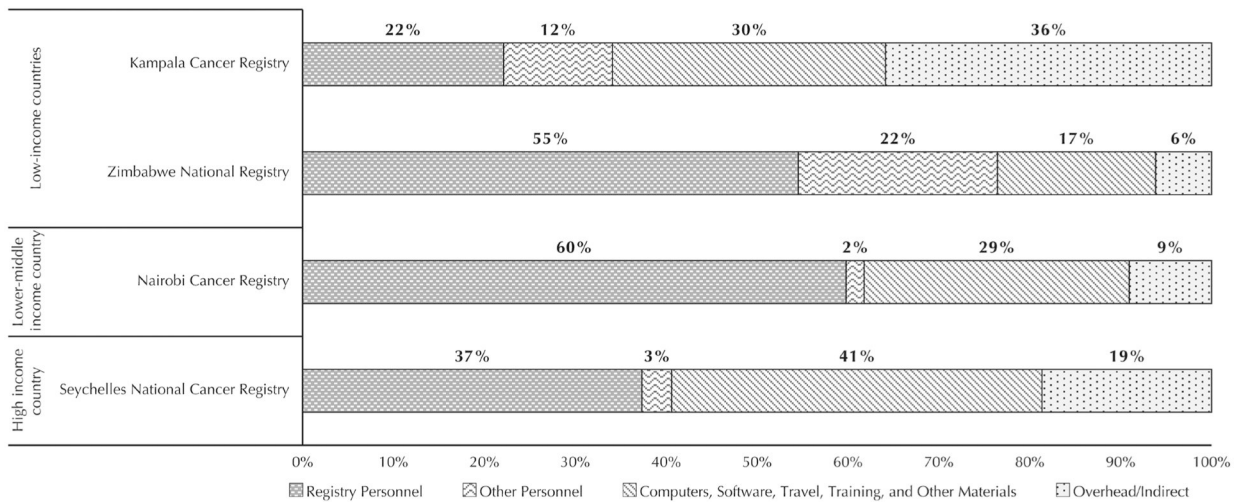


Figure 1.
African Registries’ Resources by Budget Category
 Costs were reported by cancer registry representatives for the following annual periods:
 Kampala, 2015; Zimbabwe, 2015; Nairobi, 2013; Seychelles, 2015. Other personnel relates
 to the activities performed by consultants or through contract to external personnel not from
 within registry.

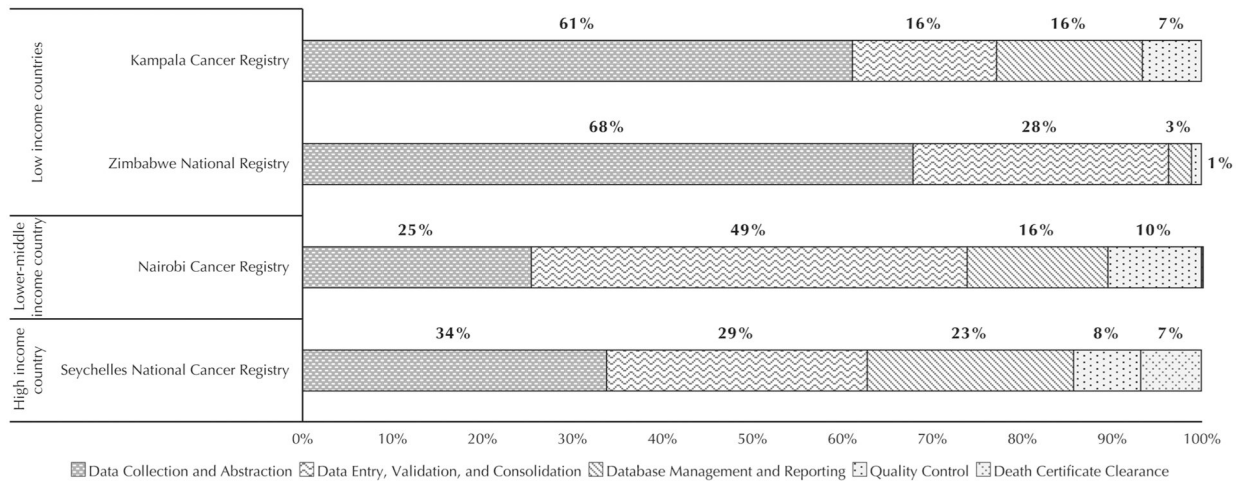


Figure 2.
Distribution of Registries' Core Activities
 Costs and activities performed were reported by cancer registry representatives for the following annual periods: Kampala, 2015; Zimbabwe, 2015; Nairobi, 2013; Seychelles, 2015.

Table 1.

Comparison of the Basic Characteristics of the African Cancer Registries

	Kampala Cancer Registry	Zimbabwe National Registry	Nairobi Cancer Registry	Seychelles National Cancer Registry
Country	Uganda	Zimbabwe	Kenya	Seychelles
Income category	Low	Low	Lower-middle	High
Years of operation	63	32	16	9
Host institution type	Public university	Health department	Research institute (government)	Health department
Population covered	2,700,000	13,061,239	3,400,000	96,858
Area covered (km2)	1,914	390,757	695	459
Cancer cases	1,735	6,548	2,099	172
Reportable disease	No	No	Yes	No
If yes, actively enforced?			No	
Cancer Incidence in Five Continents (CIS) inclusion	Yes	Yes	Yes	Yes
Number of sources (total)	11	23	24	10
Perform active follow-up	Yes	Yes	No	Yes
Performs death clearance	No	Yes	Yes	Yes
Sources of funding	2	5	2	2

Cancer cases corresponds to the number of cancer incidence cases and were provided by registries for the following years: Kampala, 2013; Zimbabwe, 2013; Nairobi, 2011; Seychelles, 2013. Other characteristics were provided for the following years: Kampala, 2015; Zimbabwe, 2015; Nairobi, 2013; Seychelles, 2015. Income category determined based on 2017 World Bank classification system available at <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>. Years of operation are the total operating years as of 2017.

Table 2.

Cost Per Case by Budget Category, US Dollars

	Country Income Category		
	Low Income	Lower-Middle Income	High Income
Registry	Kampala Cancer Registry	Zimbabwe National Registry	Seychelles National Cancer Registry
Registry personnel	1.90	5.70	35.68
Other personnel	1.04	2.29	3.16
Computers, travel, training, and other materials	2.59	1.80	38.26
Software	–	0.01	0.75
Overhead/indirect	3.09	0.65	17.79
Total cost per case	8.62	10.45	95.63
Total cost per inhabitant	0.01	<0.01	0.17

Costs were reported by cancer registry representatives for the following annual periods: Kampala, 2015; Zimbabwe, 2015; Nairobi, 2013; Seychelles, 2015. Cancer cases correspond to the number of cancer incidence cases during the following years: Kampala, 2013; Zimbabwe, 2013; Nairobi, 2011; Seychelles, 2013.