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*Cancer Epidemiol.* 2016 December ; 45(Suppl 1): S50–S58. doi:10.1016/j.canep.2016.10.009.**Resource requirements for cancer registration in areas with limited resources: Analysis of cost data from four low- and middle-income countries\*****Florence K.L. Tangka<sup>a,\*</sup>, Sujha Subramanian<sup>b</sup>, Patrick Edwards<sup>b</sup>, Maggie Cole-Beebe<sup>b</sup>, D. Maxwell Parkin<sup>c</sup>, Freddie Bray<sup>d</sup>, Rachael Joseph<sup>e</sup>, Les Mery<sup>d</sup>, Mona Saraiya<sup>a</sup>, and Cancer registration economic evaluation participants<sup>1</sup>**<sup>a</sup>Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, Atlanta, GA, USA<sup>b</sup>RTI International, 3040 E. Cornwallis Rd., Research Triangle Park, NC, USA<sup>c</sup>Honorary Senior Research Fellow, Nuffield Department of Population Health, University of Oxford, Richard Doll Building, Old Road Campus, Roosevelt Drive, Oxford, OX3 7LF, United Kingdom<sup>d</sup>Section of Cancer Surveillance, International Agency for Research on Cancer (IARC), Lyon, France<sup>e</sup>United States Centers for Disease Control and Prevention, Nairobi, Kenya**Abstract****Background**—The key aims of this study were to identify sources of support for cancer registry activities, to quantify resource use and estimate costs to operate registries in low- and middle-income countries (LMIC) at different stages of development across three continents.**Methods**—Using the Centers for Disease Control and Prevention's (CDC's) International Registry Costing Tool (*IntRegCosting Tool*), cost and resource use data were collected from eight population-based cancer registries, including one in a low-income country (Uganda [Kampala]),

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<sup>\*</sup>Corresponding author at: Centers for Disease Control and Prevention, DCPC 4770 Buford Highway, NE, Mailstop K-76 Atlanta, GA, USA. [fbt9@cdc.gov](mailto:fbt9@cdc.gov) (F.K.L. Tangka).

<sup>1</sup>Cancer registration economic evaluation participants: Marion Piñeros (International Agency for Research on Cancer (IARC), Lyon, France), Esther de Vries (National Cancer Institute, Bogotá Colombia and Pontificia Universidad Javeriana, Bogotá, Colombia), Constanza Pardo (National Cancer Institute, Bogotá Colombia), Nelson Arias (Manizales Cancer Registry, Manizales, Colombia), Luis Eduardo Bravo (Cali Cancer Registry, Cali, Colombia), Edgar Navarro (Barranquilla Cancer Registry, Barranquilla, Colombia), Claudia Uribe (Metropolitan Area of Bucaramanga Cancer Registry, Bucaramanga, Colombia), Maria Clara Yopez (Cancer Registry of Pasto, Pasto, Colombia), Daniel Jurado (Cancer Registry of Pasto, Pasto, Colombia), Luz Stella Garci (Cali Cancer Registry, Cali, Colombia), Anne Korir (Nairobi Cancer Registry, Nairobi, Kenya), Robai Gakunga (Independent Research Scientist, Nairobi, Kenya), Nathan Okerosi (Nairobi Cancer Registry, Nairobi, Kenya), Victor Rono (Nairobi Cancer Registry, Nairobi, Kenya), Henry Wabinga (Kampala Cancer Registry, Kampala, Uganda), Sarah Nambooze (Kampala Cancer Registry, Kampala, Uganda), Phoebe Mary Amulen (Kampala Cancer Registry, Kampala, Uganda), Shrivani Koyande (Mumbai Cancer Registry, Mumbai, India), Rajesh Dikshit (Tata Memorial Hospital, Mumbai, India), Vinay Deshmane (Mumbai Cancer Registry, Mumbai, India).

**Conflicts of interest**

None.

two in lower to middle-income countries (Kenya [Nairobi] and India [Mumbai]), and five in an upper to middle-income country (Colombia [Pasto, Barranquilla, Bucaramanga, Manizales and Cali cancer registries]).

**Results**—Host institution contributions accounted for 30%–70% of total investment in cancer registry activities. Cancer registration involves substantial fixed cost and labor. Labor accounts for more than 50% of all expenditures across all registries. The cost per cancer case registered in low-income and lower-middle-income countries ranged from US \$3.77 to US \$15.62 (United States dollars). In Colombia, an upper to middle-income country, the cost per case registered ranged from US \$41.28 to US \$113.39. Registries serving large populations (over 15 million inhabitants) had a lower cost per inhabitant (less than US \$0.01 in Mumbai, India) than registries serving small populations (under 500,000 inhabitants) [US \$0.22] in Pasto, Colombia.

**Conclusion**—This study estimates the total cost and resources used for cancer registration across several countries in the limited-resource setting, and provides cancer registration stakeholders and registries-with opportunities to identify cost savings and efficiency improvements. Our results suggest that cancer registration involve substantial fixed costs and labor, and that partnership with other institutions is critical for the operation and sustainability of cancer registries in limited resource settings. Although we included registries from a variety of limited-resource areas, information from eight registries in four countries may not be large enough to capture all the potential differences among the registries in limited-resource settings.

### Keywords

Economic evaluation; Cost; Cancer registries; Low- and middle-income countries; Africa; India; South america; Surveillance; Cancer control

## 1. Introduction

Health systems in the limited-resource setting currently face a rapidly increasing burden from noncommunicable diseases (NCDs), with at present, 80% percent of NCD-related deaths falling on these populations [1]. With an estimated 14.1 million new cancer cases, 8.2 million deaths, and 32.5 million people living after cancer diagnosis (cancer survivors) worldwide in 2012, cancer is a leading cause of illness and early death [2]. More than 50% of the world's cancer cases and 65% of cancer deaths occur in the limited-resource settings of the world, and more than 48% of cancer survivors live in these areas [3]. In the next two decades, new cancer cases are projected to increase by 70% worldwide—predominantly in limited-resource settings [4]. Cancer is responsible for one in three premature deaths from NCDs [5]. Cancer, along with diabetes, chronic respiratory disease, and cardiovascular disease were prioritized for action at the United Nations General Assembly on NCDs in 2011 [6].

High-quality population-based cancer surveillance data are needed to: (1) describe cancer burden, patterns, and outcomes in order to (2) inform cancer prevention, detection and control activities; and (3) evaluate interventions on the basis of past and future trends so that optimal approaches to alleviate burden and suffering from cancer can be adopted. There are large inequalities in the existence, coverage, and quality of cancer surveillance systems

across the world, with limited information currently available in the limited-resource setting [7]. 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) ranges from nearly 100% in North America to less than 10% in Asia, Central America, and South America, and approximately 2% in Africa [8,9].

Only one in five countries in the limited-resource setting have the data needed to inform cancer control plans and reduce the burden from cancer [5]. To address this gap, the International Agency for Research on Cancer (IARC), a specialized agency of World Health Organization (WHO), has initiated the Global Initiative for Cancer Registry Development (GICR) [5] to establish regional resource centers to provide technical support and guidance for the development and improvement of population-based cancer registries around the world.

IARC has developed a framework for planning and implementing population-based cancer registries [9]. However, lack of accurate and reliable costing data is a major limitation to global, regional, and country efforts to plan, implement, and evaluate investments in cancer registration. The objectives of this study are therefore to (1) identify sources of funding and distribution of total resources by source; (2) determine the proportion of registry resources allocated to activities with variable and fixed costs, and the percentage of total resources allocated to labor; and (3) estimate operating cost per cancer case registered (cost per case) as well as the cost per inhabitant served (cost per inhabitant).

## 2. Material and methods

We collected data on the cost of registry operations (including funding and in-kind contributions) and resource utilization using a standardized data collection instrument, the US Centers for Disease Control and Prevention's (CDC's) International Registry Costing Tool (*IntRegCosting Tool*) [10]. The *IntRegCosting Tool* is based on a previously tested and validated instrument used to collect data from the CDC-supported state cancer registries in the US and extensively tailored for use in diverse types of registries [11]. The tool consists of 10 data collection modules that cover funding, cost and resource use, as well as registry characteristics. Cost data were collected for the following budget categories: labor, consultants, computers, travel, training, and other materials, software, and administrative or overhead. The distribution of registry resources by budget category is shown in Subramanian et al. [10]. Using a programmatic perspective, all costs and resource use relevant to program operations were collected. Therefore, all monetary and nonmonetary contributions to registry activities were available for a comprehensive assessment, representing the value of all resources required to operate a registry.

The *IntRegCosting Tool* included a data collection module to collect in-kind contributions, which included donated labor and non-labor resources. For example, the cost of donated labor was estimated using the average hourly wage for a person with similar qualifications obtained from national wage statistics. Additionally, we also estimated all the resources provided by the host institution whether through direct payments, such as staff salaries, or non-monetary contributions, such as office space or IT support.

For this study, a convenience sample of eight regional population-based registries was selected from four countries that have on going or planned future collaboration with CDC on noncommunicable disease prevention and control efforts. Registries were selected to provide variation in geographic location, income category, case volume, and size of population covered. One year of data was collected from the registry in Kampala, Uganda (2014), four registries in the state of Maharashtra, India (Mumbai, Nagpur, Aurangabad and Pune in the fiscal year 2014–2015), and five registries in Colombia (Pasto, Barranquilla, Bucaramanga, Manizales, and Cali in fiscal year 2013). Two years of data were collected from Nairobi, Kenya (July 2012–June 2014). Registry staff collected cancer incidence data from medical facilities with which they had data sharing agreements or memoranda of understanding.

A user's guide with standardized definitions and ongoing technical assistance were provided to registry staff and in-country consultants who assisted the registries. The in-country consultants helped ensure a clear understanding of terms among their country's participating registries, including language translation in Colombia. Staff from each registry provided feedback on the definitions and classification of registry activities, and provided active input in developing the user's guide. The research team provided technical assistance to registries at every stage of the data collection process via site visits, webinars, telephone calls, and e-mail. Training and webinars were held with the research team, in-country consultants, and registry staff at regular intervals to ensure that all participants and collaborators had a clear understanding of the data elements and process for completing the *IntRegCosting Tool*. During the webinars, the research team provided examples of the cost data collection tool and shared high-level results from the economic analysis of US cancer registries [12] to show the value of the project and how the data can be used.

Costs were reported by registries using their local currency and converted to United States dollars (US \$) using the official rate that corresponds with the year the costs were incurred (2013 for the Colombian registries and 2014 for the Indian registries, Nairobi and Kampala). Once the data were submitted, a series of data quality assessments were performed to ensure accuracy of the information. We assessed whether costs were allocated to all appropriate budget categories and whether all monetary contributions received from funding sources were assigned to specific registry activities. Registries had to allocate at least 90% of their costs to registry activities in order to meet the threshold for high-quality cost data. This threshold was determined based on prior work with registries funded by the CDC in the United States [10–12]. All registries met this standard. Additionally, we reviewed whether costs specifically related to labor were assigned to all core registry activities of data collection, analysis, and reporting for each annual period by reviewing the labor contribution by specific registry activity. When queries arose during the quality review process, the research team worked with registry staff and in-country consultants to clarify and correct data as needed before finalizing each data submission.

After data analysis, descriptive statistics were generated on registry characteristics, resources by budget category, and cost by registry activity. Registry activities were categorized into fixed-and variable-cost activities. Fixed-cost activities (those expected to not vary in cost in the short run as volume of cases change) included management, administration, training of registry staff, and IT support. Variable-cost activities (those expected to vary in cost as

volume of cases change) consisted of case ascertainment, data abstraction, data collection, data validation, and quality review, which were essential for registry operations, along with training of others by registry staff and research activities, which were not essential for registry operations. Detailed descriptions of all registry activities, along with the definitions, have been previously reported [10].

To compare cost of operations across registries, we calculated cost per cancer case registered (cost per case) and cost per inhabitant served (cost per inhabitant). Cost per case was calculated as total registry operating costs (including funding and in-kind contributions) divided by the number of incident cases diagnosed during a typical annual period. Cancer registries collect and process cases across multiple years in any given time period, and complete data for any case may only be available for a certain number of years; therefore, using data from a single year has been shown to be a good approximation for case load for most registries [11,13]. Cost per inhabitant was calculated as total registry operating costs for the period divided by the total population of the cancer registry coverage area. We report cost per case and cost per inhabitant in both US \$ based on year of cost data collection and 2011 purchasing power parity (PPP) [14]. PPP reflects a country's ability to purchase a standardized set of goods and services, facilitating comparisons across countries. The PPP is the number of units of a country's currency required to buy the same amounts of goods and services in the given nation as the US \$ would buy in the US. Thus, the PPP standardizes costs across countries using a common reference point: the US \$. The US \$, as the reference currency, is equal to unity. Reporting cost information in a common currency is a standard approach in health economics and one that is recommended by WHO [15].

### 3. Results

Table 1 presents the characteristics of the registries studied and clearly highlights the diversity of the registries included in this study. Registries from WHO regions of Africa, Asia, and the Americas are included and represent countries with low-, lower-middle-, and upper-middle-income countries. Four of the registries are based in a public university, two in a private university, one in a government research institute, and one in a private, non-government organization. With the exception of the Nairobi registry, all registries have a continuous funding cycle. The average annual case volume among the registries ranges from 726 incident cases diagnosed in Manizales, Colombia, to 19,485 in Mumbai, India. The size of the population covered as reported by the cancer registries ranges from 390,084 (Manizales, Colombia) to 17,443,311 (Mumbai, India). The square kilometers covered ranges from 121 (Cali, Colombia) to 1914 (Kampala, Uganda). For most registries, cancer was not a reportable disease by national or regional legislation during the period of data collection, with the exceptions of Nairobi, Kenya and Pasto, Colombia. Registries considered to have high quality data are those that meet completeness, accuracy, and coverage criteria required for inclusion in the last volume of CI5 [16]. Most registries in our study had high quality data included in this global compendium of cancer incidence, with the exceptions of Nairobi and Barranquilla.

Sources of registry contributions include host institutions (such as a local university), national or local cancer or health organizations (such as the Colombian National Cancer

Institute), IARC, and other entities (supporting specialized studies). Fig. 1 presents the distribution of total resources by contribution source for each registry. Contributions from the host institutions (e.g. Kenya Medical Research Institute in Nairobi; Makerere University in Kampala; the Indian Cancer Society in Mumbai; and universities in Barranquilla, Bucaramanga, Cali, Manizales, and Pasto) provided valuable support for registry activities and accounted for 30% (Nairobi, Kenya) to 70% (Bucaramanga, Colombia) of registry operating resources. National or local organizations also provided substantial resources for registry operations in Colombia and Mumbai, ranging from 28% in Cali to 50% in Barranquilla. Most of these resources were provided to Colombian registries by the Colombian National Cancer Institute, and to Mumbai registry by India's National Program of Cancer Registries. Support by international organizations, such as IARC or the International Network for Cancer Treatment and Research (INCTR), contributed to a large portion of the African countries' resources, ranging from 42% in Kampala, Uganda to 70% in Nairobi, Kenya.

Cancer registries incurred significant fixed costs, accounting for nearly 20% (Bucaramanga, Colombia) to 45% (Manizales, Colombia) of total operating resources, as reported in Fig. 2. Cancer registry activities are labor intensive. Fig. 3 reports the percentage of total operating resources allocated to labor. Registries with a higher share of operating resources devoted to variable activities (Fig. 2) had a higher percentage of total resources allocated to labor (Fig. 3). Table 2 shows the total number of staff full-time equivalents (FTEs) by cancer registry, the percentage of FTE by labor category, and the number of cancer cases per staff. Mumbai, India, including satellite registries, employs the largest number of staff (31 FTE), which is related to the large population covered. It has the largest number of cancer incident cases out of all the registries studied. Meanwhile, the Kampala Cancer Registry, which is located in the lowest income country in this study, had the smallest number of total staff (3 FTEs). The Manizales registry in Colombia also had a small number of total staff (3.6 FTEs), which is reflective of this registry having the smallest population within the registry coverage area and also the smallest number of cancer incident cases. On average, registrars and data collectors contributed to a little over half (58%) of the total staff for most registries, but there was a wide range by registry (28%–94%). Management and administrative staff ranged from 6%–33% of total staff, while staff whose primary role was database management or research ranged from 0%–55%. Kampala, Uganda did not have any staff whose primary role was database management or research; however, did receive assistance with these activities through IARC consultants. Pasto, Colombia and Nairobi, Kenya also reported no staff with the primary role as research. Registries in low and lower middle income countries had a significantly higher number of cancer cases per staff than registries in Colombia, an upper middle income country. Pasto, Colombia had the smallest number of cancer incident cases per staff (116) while Kampala, Uganda had the largest number of cancer incident cases per staff (636).

Table 3 presents the cost per case and cost per inhabitant for each registry, both in US \$ and PPP terms. Registries of low- and lower-middle-income countries had a significantly lower cost per case (ranging from 14.96 PPP [US \$3.77] in Mumbai, India, to 39.62 PPP [US \$15.62] in Nairobi, Kenya) compared with registries in upper-middle-income countries (ranging from 67.07 PPP [US \$41.28] in Barranquilla, Colombia, to 184.25 PPP [US

\$113.39] in Pasto, Colombia). Cost per inhabitant was related to size of population covered by the registry. Registries serving large populations (over 17 million inhabitants) had a lower cost per inhabitant (0.02 PPP [less than US \$0.01] in Mumbai, India) than registries serving small populations (below 500,000 inhabitants) (0.36 PPP [US \$0.22] in Pasto, Colombia). Cali, an established registry with significant resources devoted to special research projects, is an outlier among registries serving populations 2 million or higher, with a cost per inhabitant of 0.29 PPP (US \$0.18).

#### 4. Discussion

This is the first study to estimate the total cost and resources used for cancer registration across several countries in the limited-resource setting. Understanding such sources of funding, the allocation of resources, and the true cost of cancer registration serves multiple purposes: planning funding requirements, identifying resources required to improve and expand data collection activities, informing the establishment of new registries, and assessing efficiencies in data collection approaches. Of the limited number of studies that have been conducted on the economics of cancer registration, the majority are on CDC-supported state cancer registries in the US [11–13,17–19]. Very few involve multiple countries [20,21]. Comparative analyses of the cost of registry operations across countries is challenging given national and regional differences in economic profiles, history, clinical and administrative background, and study approach [21]. A previous study used direct funding sources to estimate the cost per case for registries in the African Cancer Registry Network but did not include in-kind contributions, understating the true cost of operating a cancer registry [20]. Another previous study found comparable results for the Colombian registries, but used a more basic methodology that may have underestimated the costs for the lower-cost registries due to not accounting for all in-kind costs or funding from all sources [22]. To understand the total cost of cancer registration, it is essential to acknowledge the contributions made by all partners and to accurately assess the resources required for establishing, expanding, and enhancing cancer registry activities.

Partnerships are critical for the sustainability of cancer registries. The registries in this study did not operate as independent (single or stand-alone) entities; each one was part of an established institution, such as a university, hospital, medical research center, or nonprofit institution (e.g. a Cancer Society). Host institutions on average contributed 56% of the total value of resources needed to operate cancer registries, but there was wide range by registry (30%–70%). Host institutions provide significant in-kind contributions. For example, these institutions provide office space and utilities, some personnel (e.g., program directors and administrative assistants, whose salaries are fully or partially paid by the host institution because they assume other duties for the host institution), information technology support, transportation, and office supplies. Other partners also contribute to the success of cancer registration. For instance, IARC provides free software (CanReg5) [23] and technical assistance. One of the aims of the GICR, coordinated by IARC as an international partnership, is to help strengthen, expand, or establish new cancer registries in limited-resource settings via the establishment of Regional Hubs. IARC also provides some financial support for registries in Africa. In Colombia, where population-based registries are institutionalized, the Colombian National Cancer Institute conducts annual reviews and

provides funding (in cash) and technical support for the operation of the registries based on findings from the reviews and site visits.

The distribution of resources by activities shows that substantial fixed costs are associated with registry activities. At least 20% of the total value of resources was associated with fixed costs (range 20%–45%). These fixed costs can relate to facilities and other infrastructure required for data processing and reporting, and some personnel salaries (e.g. registry director). Regardless of the case volume of a particular registry, fixed resources are needed. Therefore, sharing of fixed costs among small-volume registries or countries of a particular region, whenever possible, and centralization of certain processes, may help reduce the overall cost of cancer registration. For example, the Mumbai Cancer Registry and its three satellite registries in Pune, Nagpur, and Aurangabad, share registry operation costs. Data collectors at the satellites perform data abstraction, but Mumbai carries out all other core registration activities such as data analysis and quality assurance. Another example is the Barbados National Registry (BNR) for Chronic Noncommunicable Diseases (NCD) that registers both cancer and cardiovascular disease (CVD) cases. By using an integrated approach to NCD case registration, BRN shares fixed cost across registration of cancer and CVD cases. A study of CDC-supported state cancer registries in the US identified similar opportunities for low-volume registries to share resources to reduce cost of registry operations [12].

On average, labor accounted for about 68% (range 53%–93%) of the value of total resources of cancer registration, which reflects the labor-intensive nature of cancer registration. Labor is generally the highest cost component among all registries, including those in previous studies in the US and Europe [12,21]. The findings of this study highlight the potential for passive data reporting and automated processes that can increase efficiency through technology, reduce labor cost, and improve quality of the data. One potential approach can be to have, cancer registrars abstract data via (encrypted) electronic handheld devices, such as laptops or tablets instead of manually completing paper forms. Another potential approach is to modify the current data infrastructure that exists in the provider sites and hospitals to improve data collection efforts, including passive data reporting.

The underreporting of cancer incidence can add challenges to registries wishing to pursue more-passive data collection. It is relatively common for patients to take their medical files and reports home, which make them unavailable at provider sites and hospitals for data abstraction. Furthermore, clinicians do not routinely report cancer cases because cancer reporting is not mandated by law, as was the case in the majority of the registries. The underreporting of cancer incidence can be addressed by making cancer a reportable disease, by requiring a wide range of health care providers to report cases to cancer registries or by allowing registry staff access to their data. In some instances, additional financial and non-financial resources may be needed to fulfill the reporting requirements. These mandates could reduce the workload and cost of cancer registry staff who find and abstract the cancer data, and decrease the time and resources needed by program managers to establish relationships and reporting agreements with data sources. Nevertheless, even in settings where cancer is a reportable disease, some level of active data collection will be needed.



Cost per case and cost per inhabitant varied across registries. Cancer registries in low-income countries had lower costs than registries in upper-middle-income countries. In a prior analysis in a high-income country, the main drivers of cost were case volume, size of area served, and quality of data available from providers [12]. The Mumbai registry, to highlight the impact of volume, collects data on the largest number of cancer cases among all the registries included in this study, and has the lowest cost per case. Other cost drivers could include cost of living, number of data sources, how records are stored, method of case finding (generally active rather than passive), method of data abstraction (largely using paper forms rather than electronic devices), requirements of annual renewal of agreements for data collection, size of the areas served by the registry [10], types of positions, and total number of staff per registry. For example, registries that rely on active case finding will need more resources related to travel and data collection labor if the registry covers a large geographic area. Registries in this study also varied in the data collection methods, with the African registries relying almost fully on paper-based methods, and Colombian registries reporting more of a mixture between paper and electronic-based methods. See Subramanian et al. for additional details on the internal and external factors that affect registry cost and data quality [10].

Overall, the cost of cancer registry operations per inhabitant is less than US \$1, and is therefore a very small investment on a per-capita basis for the benefits of high quality information for cancer control that could be used toward reducing the enormous financial and nonfinancial burden from cancer [24,25].

Although this study provides the first comprehensive analysis of the total resources required to operate cancer registries in the limited-resource setting, it does have limitations. One of the potential limitations of the data analysis presented in this study is that the registries report data retrospectively; the potential for recall error makes the reliability of retrospective data uncertain. A second limitation is the geographic diversity of the registries. Although the cost data were converted from local currency to US \$ and PPP to make comparison across countries easier and to account for regional variation, differences in costs between registries may persist. A third limitation is reporting information about cancer cases, which involves data collection for each case that may span several years. Thus, there may be a mismatch in aligning registry cost to the specific cases reported because of a lag in the reporting of cancer cases. Furthermore, registry funding from external sources can vary, so the 1-year estimates provided in this study may not be an accurate estimate of long-term trends. Additional rounds of data collection would allow for more stable estimates of the true cost of cancer registration. A fourth limitation in conducting this study is that the registries are part of large institutions, most of which have no formal budget and receive support from multiple sources, so it was difficult to account for total value of resources required to operate cancer registries. Thus, it is possible that these analyses underestimated the true costs of cancer registry operations. Zanetti et al. [21] observed a similar issue in conducting the economic evaluation of cancer registries in Europe. Fifth, although we verified that the quality of the economic data collected was high, we did not collect information on the quality of the cancer case data collected. We used inclusion in CI5 as our quality measure, and additional approaches to assess quality of the cancer case data may be needed. Therefore, the true cost of cancer registry operations may be understated if a registry is not

able to meet CI5 quality standards because of insufficient resources to produce high-quality data. Finally, even though we were able to include registries from a variety of limited-resource areas, the overall sample size of the panel data of eight registries in four countries may not be large enough to capture all the potential differences among the registries in limited-resource settings.

## 5. Conclusions

This study provides information about the sources of support for cancer registry activities, the proportion of resources allocated to activities with fixed versus variable costs and to labor, and the total cost of operating cancer registries (including cost per case and cost per inhabitant). Such information is needed for efforts to establish, enhance, and expand cancer registration in limited-resource settings. This information can also provide cancer registration stakeholders and registries with opportunities to identify cost savings and efficiency improvements. Based on the findings from this study, registries have already begun assessing ways to improve their operations. For example, Kenya is using the cost data to plan its expansion of cancer registration to increase national coverage, and Colombian registries are assessing ways to increase operational efficiency. This study looked at a diverse range of registries from various countries and in various stages of development. Given the limited number of registries who participated, we need to collect cost data from an even larger number of cancer registries to derive the average cost of registering a cancer case in a region. This study has provided motivation for the current stage of the project, which is to expand use of the costing tool to a wider range of countries.

## Author contributions

Florence Tangka: Lead author; manuscript conception and design; acquisition, analysis and interpretation of data; drafted the manuscript; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Sujha Subramanian: Co-author; manuscript conception and design; acquisition, analysis and interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Patrick Edwards: Co-author; acquisition, analysis and interpretation of data; figure/table creation; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Maggie Cole-Beebe: Co-author; cost data collection tool design and validation; interpretation of data; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Maxwell Parkin: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

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Freddie Bray: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Rachael Joseph: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Les Mery: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Mona Saraiya: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Marion Pineros: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Esther de Vries: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Constanza Pardo: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Nelson Arias: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Luis Eduardo Bravo: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Edgar Navarro: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Claudia Uribe: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Maria Clara Yopez: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Daniel Jurado: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Luz Stella Garci: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Anne Korir: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Robai Gakunga: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Nathan Okerosi: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Victor Rono: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Henry Wabinga: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Sarah Nambooze: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Phobe Mary Amulen: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Shravani Koyande: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Rajesh Dikshit: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Vinay Deshmane: Co-author; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

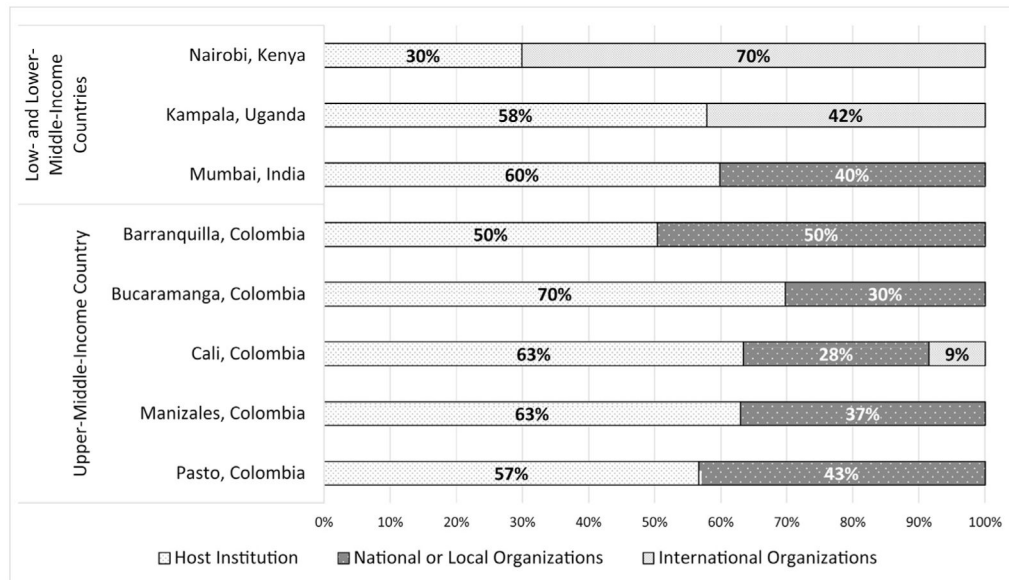
## Abbreviations

<b>CI5</b>	Cancer Incidence in Five Continents
<b>CDC</b>	Centers for Disease Control and Prevention
<b>FTE</b>	full-time equivalent
<b>FY</b>	fiscal year
<b>GICR</b>	Global Initiative for Cancer Registry Development
<b>IARC</b>	International Agency for Research on Cancer
<b>INCTR</b>	International Network for Cancer Treatment and Research
<b><i>IntRegCosting Tool</i></b>	International Registry Costing Tool
<b>IT</b>	information technology
<b>LMIC</b>	low- and middle-income countries
<b>NCDs</b>	noncommunicable diseases
<b>PPP</b>	purchasing power parity
<b>US \$</b>	United States dollars
<b>WHO</b>	World Health Organization

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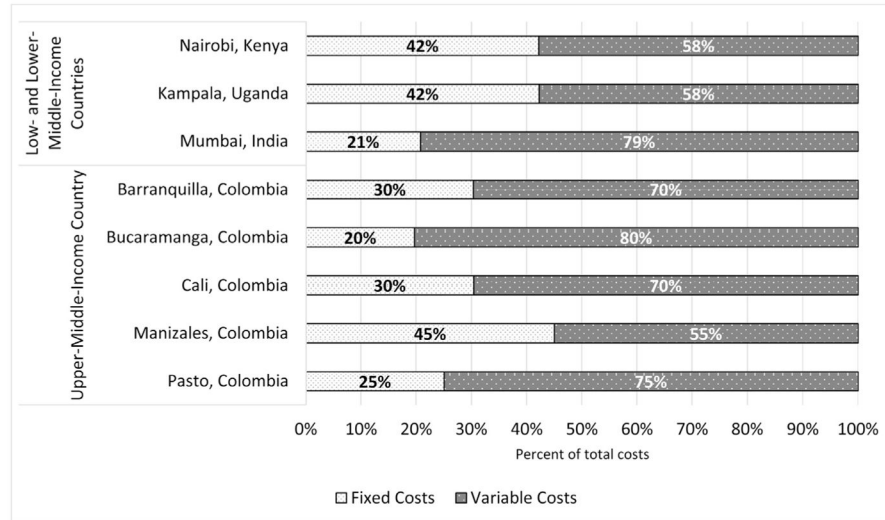
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**Fig. 1.**  
Distribution of Total Resources by Source.

*NOTES:* The costs were reported by cancer registry representatives for the following periods: Nairobi annual average July 2012–June 2014; Kampala 2014; Mumbai FY 2014–2015; Colombian registries 2013.

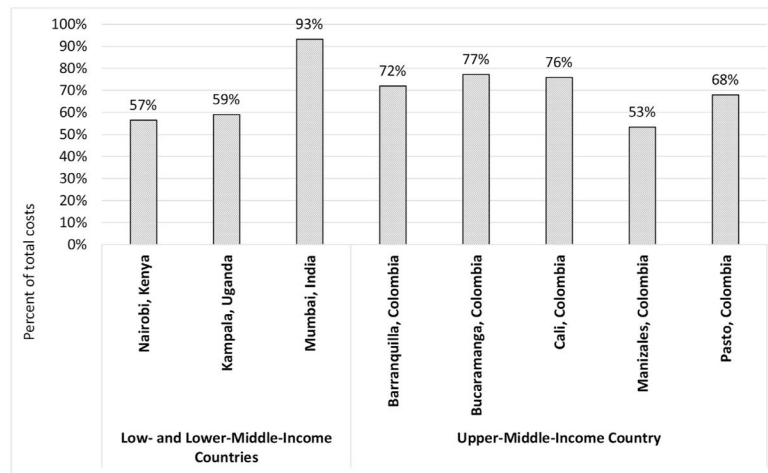


**Fig. 2.**  
Allocation of Resources to Fixed and Variable Costs.

*NOTES:* The costs were reported by cancer registry representatives for the following periods: Nairobi annual average July 2012–June 2014; Kampala 2014; Mumbai FY 2014–2015; Colombian registries 2013.

Variable costs are inclusive of core registry activities, which are essential for registry operations, as well as other registry activities, such as enhanced analysis and research related tasks.





**Fig. 3.** Percentage of Total Registry Costs Devoted to Labor by Cancer Registry.

*NOTES:* The costs were reported by cancer registry representatives for the following periods: Nairobi annual average July 2012–June 2014; Kampala 2014; Mumbai FY 2014–2015; Colombian registries 2013.

Table 1

Cancer Registry Characteristics.

Registry	Nairobi	Kampala	Mumbai <sup>a</sup>	Barranquilla	Bucaramanga	Cali	Manizales	Pasto
WHO region <sup>b</sup>	AFRO	AFRO	SEARO	PAHO	PAHO	PAHO	PAHO	PAHO
IARC hub region	Sub-Saharan Africa	Sub-Saharan Africa	South, South-east and Eastern Asia	Latin America	Latin America	Latin America	Latin America	Latin America
Country	Kenya	Uganda	India	Colombia	Colombia	Colombia	Colombia	Colombia
Income category <sup>c</sup>	Lower middle	Low	Lower middle	Upper middle	Upper middle	Upper middle	Upper middle	Upper middle
GDP per capita 2014 (US \$) <sup>c</sup>	1358	715	1582	7904	7904	7904	7904	7904
GDP per capita 2014 (PPP) <sup>c</sup>	2954	1771	5701	13,357	13,357	13,357	13,357	13,357
Host institution type	Research institute (government)	Public university	Private NGO (non-government organization)	Private university	Private university	Public university	Public university	Public university
Funding cycle <sup>d</sup>	Intermittent	Continuous	Continuous	Continuous	Continuous	Continuous	Continuous	Continuous
Average annual cancer cases <sup>e</sup>	5191	1907	19,485	1450	2124	5027	726	809
Population covered <sup>f</sup>	3,135,000	2,629,132	17,443,311	1,189,503	1,084,699	2,333,016	390,084	417,484
Area covered (sq KM) <sup>f</sup>	696	1914	1234	166	1479	121	572	1181
Reportable disease <sup>f</sup>	Y	N	N	N	N	N	N	Y
CIS inclusion <sup>g</sup>	N	Y	Y	N	Y	Y	Y	Y

NOTES:

<sup>a</sup>Mumbai Cancer Registry includes three satellite registries.<sup>b</sup>AFRO, Regional Office for Africa; SEARO, Regional Office for South-East Asia; PAHO, Pan American Health Organization.<sup>c</sup>Income categories and GDP information from the World Bank can be found at <http://data.worldbank.org/about/country-and-lending-groups>.<sup>d</sup>Colombian registries are funded following annual reviews.<sup>e</sup>For incident cases diagnosed numbers, we used the following annual periods: Nairobi annual average; Kampala 2012 cases; Mumbai 2012 cases; Colombian registries 2010 cases.

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<sup>f</sup> Coverage area population, square kilometers, and reportable disease status reported by cancer registry representatives.

<sup>g</sup> Registries that are included in Cancer Incidence in Five Continents (CI5), retrieved from <http://ci5.iarc.fr/CI5-X/Pages/Table21.aspx>.

**Table 2**

Registry Staff Full-Time Equivalent (FTE) by Labor Category and Cancer Cases per Staff.

Registry	Income level	Total number of staff FTE <sup>a</sup>	Management and Administrative	Registrars and data collectors	Database management and IT support	Researchers, investigators, and medical personnel	Cancer cases per staff <sup>b</sup>
Nairobi	Lower middle	9.9	30%	55%	15%	0%	524
Kampala	Low	3	6%	94%	0%	0%	636
Mumbai	Lower middle	31	10%	55%	26%	9%	629
Barranquilla	Upper middle	6.12	33%	49%	16%	2%	237
Bucaramanga	Upper middle	8.5	17%	59%	12%	12%	250
Cali	Upper middle	13.35	15%	67%	8%	10%	377
Manizales	Upper middle	3.6	14%	28%	55%	3%	202
Pasto	Upper middle	7	14%	57%	29%	0%	116

**NOTES:**

<sup>a</sup>The staff were reported by cancer registry representatives for the following periods: Nairobi annual average July 2013–June 2014; Kampala 2014; Mumbai FY 2014–2015; Colombian registries 2013.

<sup>b</sup>For incident cases diagnosed, we used the following annual periods: Nairobi annual average; Kampala 2012 cases; Mumbai 2012 cases; Colombian registries 2010 cases.

**Table 3**

Cost per Cancer Case Registered and Cost per Inhabitant Served by Registry.

Registry	Income Level	Cost per Cancer Case <sup>a</sup> (US \$) <sup>b</sup>	Cost per Cancer Case <sup>c</sup> (PPP) <sup>d</sup>	Cost per Inhabitant <sup>e</sup> (US \$)	Cost per Inhabitant (PPP)
Nairobi	Lower middle	15.62	39.62	0.03	0.07
Kampala	Low	10.22	33.83	0.01	0.02
Mumbai	Lower middle	3.77	14.96	<0.01	0.02
Barranquilla	Upper middle	41.28	67.07	0.05	0.08
Bucaramanga	Upper middle	57.51	93.45	0.11	0.18
Cali	Upper middle	81.81	132.94	0.18	0.29
Manizales	Upper middle	67.40	109.52	0.13	0.20
Pasto	Upper middle	113.39	184.25	0.22	0.36

**NOTES:**

<sup>a</sup>The costs were reported by cancer registry representatives for the following periods: Nairobi annual average July 2012–June 2014; Kampala 2014; Mumbai FY 2014–2015; Colombian registries 2013.

<sup>b</sup>Currency converted from local currency to US \$ for Nairobi, Kampala, and Mumbai during 2014 and all Colombian registries during 2013.

<sup>c</sup>For incident cases diagnosed numbers, we used the following annual periods: Nairobi annual average; Kampala 2012 cases; Mumbai 2012 cases; Colombian registries 2010 cases.

<sup>d</sup>Purchasing power parity (PPP), 2011 International Comparison Program, World Bank.

<sup>e</sup>Cost per inhabitant is defined as the total cancer registry costs for the annual period divided by the total population of the cancer registry coverage area.