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# Economic evaluation of Mumbai and its satellite cancer registries: Implications for expansion of data collection[*]

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## Abstract

**Background**—The Mumbai Cancer Registry is a population-based cancer registry that has been in operation for more than five decades and has successfully initiated and integrated three satellite registries in Pune, Nagpur, and Aurangabad, each covering specific urban populations of the Indian state Maharashtra. Data collectors at the satellites perform data abstraction, but Mumbai carries out all other core registration activities such as data analysis and quality assurance. Each of the three satellite registries follows the same data collection methodology as the main Mumbai Cancer Registry. This study examines the cost of operating the Mumbai and its satellite cancer registries.

**Methods—**We modified and used the Centers for Disease Control and Prevention's (CDC's) International Registry Costing Tool (*IntRegCosting Tool*) to collect cost and resource use data for the Mumbai Cancer Registry and three satellites.

**Results—**Almost 60% of the registration expenditure was borne by the Indian Cancer Society, which hosts the Mumbai Cancer Registry, and more than half of the registry expenditure was related to data collection activities. Across the combined registries, 93% of the expenditure was spent on labor. Overall, registration activities had a low cost per case of 226.10 Indian rupees (or a little less than 4.00 US dollars in 2014 [used average exchange rate in 2014: 1 US $ = 60 Indian rupees]).

**Conclusion—**The centralization of fixed-cost activities in Mumbai likely resulted in economies of scale in operating the Mumbai and satellite registries, which, together, report on almost 20,000 cancer cases annually. In middle-income countries like India, where financial resources are limited, the operational framework provided by the Mumbai and satellite registries can serve as a model for other registries looking to expand data collection.

## 1.0. Introduction

### 1.1. Need for cancer registration

The Mumbai region has been a host to key advancements in cancer treatment and studies in India. The country's first cancer treatment center, Tata Memorial Center, was initiated in Mumbai in 1941; since then, it has played a leading role in improving cancer outcomes. The Indian Cancer Society, founded in Mumbai in 1951, is the oldest and largest cancer organization in the country. Its objective is to reduce the suffering of cancer patients and support cancer interventions to reduce the overall burden. The Tata Memorial Center and other Regional Cancer Centers highlight the magnitude of the cancer burden in India and the need for early detection and comprehensive treatment [1–7]. India, with around 1.2 billion people, has over 1 million new cancer cases per year, and, in 2012, had just under 700,000 cancer-related deaths [8]. To improve cancer care and outcomes, it is essential to understand the magnitude and pattern of the disease as it manifests in communities, and to identify modifiable and non-modifiable risk factors [9,10]. Such observations help to organize cancer care and treatment facilities and control of the disease, as well as research into its causation for prevention and control.

### 1.2. Establishment of the Mumbai cancer registry

Mumbai, formally called Bombay, is located on India's west coast. It is the country's most populous city and the capital of the Indian state Maharashtra [11]. India's first cancer registry covering the population of greater Mumbai was established in 1963 as an entity within the Indian Cancer Society. The aim of the population-based cancer registry was to obtain reliable cancer-related morbidity and mortality data from a defined urban population.

Data collection and compilation began in 1964; before then, no continuous registration of cancer cases at the population level had been undertaken anywhere in India.

From its inception until 1975, the Mumbai Cancer Registry operated with continuous financial support from the United States' National Cancer Institute. The Government of India's Department of Science and Technology supported the registry from 1976 to 1980. Since 1982, the registry has been part of the National Center for Disease Informatics and Research-National Cancer Registry Program (NCDIR-NCRP), which is the national effort organized by the Indian Council of Medical Research (ICMR). The Mumbai Cancer Registry receives partial financial support from ICMR [12]. Although the Mumbai Cancer Registry does not receive financial support directly from the Tata Memorial Center, the registry collaborates with the center on cancer data analysis and dissemination.

There is no nationwide collection of cancer data in India. There are a total of 29 population-based and 7 hospital-based cancer registries functioning under the aegis of the NCDIR-NCRP and state or central governments [13]. National, projected cancer incidence information is based on data from regional registries.

### 1.3. Expansion through satellite registries

Due to the Mumbai Cancer Registry's success, the Indian Cancer Society decided to expand cancer registration to provide more comprehensive coverage in Maharashtra. As policy makers became more aware of the cancer burden at the local level among the urban population in Mumbai, they saw the need to study patterns of cancer incidence and cancer site patterns in geographically disperse areas of the state, among communities that exist in disparate climate and ecological zones, and that have differing dietary habits and social customs. Therefore, between 1972 and 1980, three satellite registries were established across the state: one in Pune in 1972, one in Aurangabad in 1978, and one in Nagpur in 1980 [12,14–16].

### 1.4. Goal of the economics evaluation study

The Mumbai Cancer Registry has been in operation for more than five decades and has successfully initiated and integrated satellite registries. The purpose of this economic evaluation is to provide feedback to the Mumbai and satellite registries to further improve operational efficiency and optimize resource allocation. Examining the registry's cost of operations also can provide important lessons for other registries looking to expand operations. Economic evaluation is the best methodology to assess the optimal use of labor and non-labor registry resources. Developing countries like India have limited resources for cancer control, so it is critical to identify efficient approaches that can maximize the impact of available funding. We hypothesize that the establishment of satellite registries can be a promising model for expanding cancer registration coverage area in resource-constrained settings since economies of scale can arise from sharing fixed costs of registry operations.

## 2. Materials and methods

### 2.1. Mumbai cancer registry operations

Cancer is not a notifiable disease in India, which means that hospitals and other data sources are not required by legislation to report cancer cases to cancer registries. The Mumbai Cancer Registry has adopted an active data collection methodology, including active case finding and abstraction, to collect information on cancer incidence and mortality in the predefined geographic area of the registry. The registry collects data from two major sources:

- all hospitals, nursing homes, hospices, and consultants in private practice in the coverage area,

- the Municipal Corporation of Greater Mumbai's Department of Public Health's Vital Statistics Division.

Staff members regularly visit the wards of cooperating hospitals to examine the records of reported cancer cases. Staff examine the records maintained by the pathology, hematology, and radiology departments at the hospitals, as well as the various registers in specialized surgical and medical wards. Standard data elements that are endorsed by the International Association of Cancer Registries (IACR) are collected and reported annually. Data elements collected include stage and extent of disease, TNM classification of malignant tumors, treatment, date of last contact, status at last contact. The registry also collects cases on melanoma and non-melanoma skin cancers.

The base population of India is estimated for each year from the decennial National Census Data. The population covered by the registry operations increased from 4.6 million in 1964 to approximately 12.0 million in 2012. There were a total of 3057 cancer cases recorded in 1964, compared to 13,383 cases in 2012—an increase of more than 400%. At present, the registry covers over 60 hospitals and private nursing homes in metropolitan Mumbai. The majority of hospitals in the city are maintained by the Municipal Corporation of Greater Mumbai and the state government, which are responsible for organizing medical and public health services in the city. Over the past decade, private-sector medical care services in Mumbai have grown substantially, and the number of mid-sized and large, private hospitals has increased. Cancer surgery is now provided at all major hospitals, as well as in a number of well-equipped, private nursing homes in the city.

### 2.2. Satellite registry operations

All three satellite registries follow the same data collection methodology as the Mumbai Cancer Registry, and each covers a specific urban population of Maharashtra. During 2012, the four cancer registries registered a total of 19,485 incidence cases [12,14–16]. As shown in Table 1, the satellite registries collect 31% (6102/19,485) of the total cases. The satellite registries cover smaller-sized populations than Mumbai. Also, although the Mumbai Cancer Registry covers about 603 square kilometers, Pune and Nagpur each cover about half that area, and Aurangabad covers only 50 square kilometers. Altogether, the Mumbai and satellite registries cover about 16% of Maharashtra's population [10]. Pune is a large city near Mumbai that has a similar health care infrastructure, with about 50 established private

and public hospitals that range in size, as well as nursing homes and hospice centers. Nagpur also has good health care facilities and hosts a Regional Cancer Center. Aurangabad has a few medium-sized cancer care centers and hospitals. All three satellite registries are hosted by government medical colleges, and the registry office is located in the hospital buildings.

The Mumbai Cancer Registry serves as the central coordinating entity for the satellite registries; the satellite registries are affiliated but only perform certain core activities (e.g., data abstraction). The Mumbai director is responsible for managing all four registries. Data collection activities are physically performed at the predefined geographical areas of each registry using standardized data collection forms. There is clear designation of responsibilities between Mumbai and the satellite registries—data collectors at the satellites perform data abstraction, but all other core registration activities (e.g., data analysis and quality assurance) are carried out by Mumbai Cancer Registry staff. At each satellite registry, one medical professional (called an honorary secretary) provides expert advice to guide data collection efforts. The completed data collection forms from the satellite registries are sent to the Mumbai office for coding, data entry, data analysis, interpretation, report generation, and quality review, and the Mumbai Cancer Registry serves as the central repository.

### 2.3. Cost and resource use data collection

The Centers for Disease Control and Prevention's (CDC's) International Registry Costing Tool (*IntRegCosting Tool*) was developed to collect cost and resource use data from population-based cancer registries in low- and middle-income countries. The Excel-based tool is divided into 10 modules to collect cost and in-kind contribution information across budget categories, including labor; consultants; computers, travel, training, and other materials; software; and administrative or overhead expenses. Costs are then allocated to specific registries activities. For example, staff input their total percentage time spent on the specific activities, which gets multiplied by their annual salary to derive labor cost by registry activity. A detailed description on the tool and methods are provided in Subramanian et al.; briefly, it is used to collect data from registries to assess activity-based costs and factors that impact the cost of registration operations [17].

We made slight modifications to the *IntRegCosting Tool* such as displaying costs in Indian rupees, and expanding the number of input lines depending on registry size and staff totals. We then used the 10 modules to collect information from the Mumbai Cancer Registry based on the tool's standardized activities. We applied the same overall structure to collect data from the satellite registries, but we restricted its use to relevant modules and the activities performed at the registries in Pune, Nagpur, and Aurangabad. All four registries provided detailed information on the staff employed at each location, including salaries, months employed, and proportion of time spent on specific registry activities. We used cost and resource use data reported for the fiscal year 2014–2015. Each registry was able to allocate all funding received to registry activities. In addition to the monetary contributions, the tool also captured non-monetary, in-kind contributions. For example, time spent by honorary secretaries at the satellite registries is not directly compensated; therefore, we collected the

average number of hours expended on registry activities per week and applied the average wage for similar positions to derive the in-kind contribution.

## 3. Calculations

To compare incidence rates across the four registries, we generated the age-adjusted rates for the top three cancers in each registration area. We used the coding for cancer site assignment in *Cancer Incidence in Five Continents* [18] to categorize the cancers. Using the information collected in the *IntRegCosting Tool*, we present the proportion of resources from the various sources of support for the registries. Additionally, we also report the cost by budget category related to labor and non-labor categories. We calculated labor cost using the salary or wage information provided and the amount of time spent on registry activities during the reporting period. Using the resource use data collected from the four registries, we then estimated the cost of performing each registry activity by allocating both labor and non-labor costs to specific activities. In addition to monetary contributions, we also estimated the in-kind contribution provided by the registries to reflect the additional resources provided by the host organizations to operate the registries. The honorary secretaries at the satellite registries spent an average of 2–3 h per week supervising data collection activities. We applied an average wage from similar positions (about 420 Indian rupees per hour) to derive the in-kind contribution by government medical colleges. We only collected cancer case data for one year (2012), so we did not have to adjust for inflation. All costs are reported in their original values.

## 4. Results

### 4.1. Cancer incidence in Mumbai and satellite registries

Fig.1 presents the age-adjusted incidence rates for the top three cancers in Mumbai and satellite registration areas. For males in all four registry areas, lung cancer is consistently among the top three cancers reported. The incidence rate in Mumbai is much higher than in the satellite registration areas (10.3 per 100,000 in Mumbai, compared to 5.6 to 6.9 per 100,000 in the satellite areas). The top cancers among men vary by area and include prostate, mouth, larynx, and esophagus. For women, breast cancer consistently has the highest incidence rate; this rate is also substantially higher in Mumbai than in the satellite coverage areas (33.4 per 100,000 in Mumbai, compared to 16.7 to 29.1 per 100,000 in the satellite areas). Cervical and ovarian cancer are second and third, respectively, across all the coverage areas, but there is variation in the incidence rates—cervical cancer incidence is higher in the satellite registries than in Mumbai, and ovarian cancer follows the opposite pattern.

### 4.2. Resource use for cancer registration

Fig. 2 presents the funding and in-kind contributions received by the Mumbai and satellite registries. For the annual period 2014–2015, almost 60% of the registration expenditure was borne by the Indian Cancer Society, which hosts the Mumbai Cancer Registry, and another 39% was contributed by the ICMR through the NCDIR-NCRP. The host institutions of the satellite registries—the government medical colleges—provided about 1% as in-kind

contributions. Overall, three-fourths of the total resources were allocated to the operations in Mumbai, and the remaining one-fourth to the data collection activities performed at the satellite registries (not shown).

Fig. 3 provides the proportion of registry expenditure by budget categories. Labor accounts for 93% of the combined cost of the registries, with a range from 92% to 99%. In Mumbai, a total of 21 staff were employed by the registry—10 were data collectors; 2 were responsible for filing and tracking; and the remaining 9 worked on coding, data entry, and data analyses (not shown). All employees were full-time staff members and spent 100% of their time on Mumbai and satellite registry activities. The satellite registries employed 9 staff members in total—3 in Pune, 4 in Nagpur, and 2 in Aurangabad. The registries incurred few other costs apart from the payments for the registry personnel. Indirect costs related to support services and general office operations accounted for 5% of the overall combined budget, and all other activities including computer purchases and travel accounted for 2% (Fig. 3).

To identify registry operations expenditure by activities, we report the activity-based cost for each of the four registration areas. As shown in Fig. 4, data collection and abstraction was the highest cost activity, accounting for half of the registry expenditure. As expected, the largest proportion of the data collection expenditure occurred in Mumbai, which is the largest coverage area with the largest population, and the lowest proportion was in Aurangabad, which is the registry with the smallest population covered. The second and third highest costs were incurred for administration and research activities. With the exception of management, all of the remaining activities were typically performed centrally in Mumbai, with highest expenditures incurred for database management, followed by quality assurance, and then by analyzing data and generating reports.

The cost per case for the Mumbai and satellite registries is about 226.10 Indian rupees (almost 4 US dollars in 2014 [used average exchange rate in 2014: 1 US $ = 60 Indian rupees]). The cost per case by activity for the combined Mumbai and satellite registries is in Table A1 in Appendix A.

## 5. Discussion

Cancer is not a notifiable or reportable disease in India. Despite this limitation, for more than 50 years, the Mumbai Cancer Registry and satellite registries have successfully collected and reported population-based cancer incidence and mortality data. Data from the registry has been acknowledged for its high quality that meets international standards, and, since 1964, the registry's data have been routinely included and published in *Cancer Incidence in Five Continents* [19]. The variation in age-adjusted incidence rates and the mix of high-incidence cancers shown in the study is supported by other publications [20,21].

Our economics evaluation revealed that labor is the highest cost component in the Mumbai and satellite registries. About three-fourths of the expenditures support data collection/ abstraction, quality review, analysis, and data reporting from Mumbai and the three satellite registries. The cost per case for the Mumbai and satellite registries (almost 4 US $) is quite inexpensive compared to the 61 US $ per case reported by US registries [22]. Past analysis

of cancer registries has indicated that fixed-cost components such as administration, management, and reporting requirements account for a large proportion of overall expenditures [23–25]. The relatively large number of cases and centralization of many activities in Mumbai likely resulted in economies of scale, where the fixed costs of registration can be spread across a large number of incidence cases.

The cost analysis of Mumbai and satellite registries also indicates that at least half of the registries' resources is used to support data collection. If cancer becomes a reportable disease in India, then the cancer registration system could at least partially use a passive approach for data collection, which could require less effort on the part of registry staff. Mandatory reporting of cancer cases in India could help the registry increase its economic efficiency and also likely improve data accuracy. Even with mandatory reporting requirements, some level of active data collection may likely be required.

Our experience has shown that high-quality operations at the satellite cancer registries depend on a high degree of coordination between the central and satellite registries. However, despite good working relationships, the registry's day-to-day management still poses many challenges. The main issue, probably similar to other population-based cancer registries, is ensuring cooperation of the various sources to allow registry staff to access confidential medical records. To maintain patient confidentiality, many hospitals hesitate to share medical record information with the cancer registry staff. Due to distance and a lack of local knowledge, it is not possible for central registry staff to sort out such problems that arise in the satellite registry coverage areas. The honorary secretaries at each satellite registry play a vital role in dealing with issues related to data collection that arise in their local context; for example, they can assure the hospitals that the registry will maintain strict confidentiality.

The experience of the Mumbai Cancer Registry clearly highlights the need for support from multiple stakeholders to successfully operate cancer registration activities. During its early years, the registry was financially supported by the United States National Cancer Institute and the Government of India's Department of Science and Technology. The registry is currently supported by the Indian Cancer Society and the NCDIR-NCRP. Additionally, the collaborating government medical colleges serve as key partners in collecting data from other urban areas of Maharashtra, and they support cancer registration through in-kind contributions. Finally, the Mumbai Cancer Registry is also working with Tata Memorial Center on various research initiatives that use the data from the Mumbai and satellite registries. Successful cancer registration initiatives therefore require multilayered partnerships that include funders, data collection partners, and research collaborators to disseminate findings.

There are a few limitations to the economic evaluation presented in this study. Although we attempted to capture the in-kind contributions provided to the registries, we may not have fully captured all contributions made by the host institutions to support registry operations. Additionally, we only report on the cost of operating smaller and larger urban-based registries. Past research shows that patterns in cancer incidence vary between urban and rural areas, and therefore coverage in both areas is required for a complete assessment of cancer

incidence and mortality [26]. We are in the process of analyzing cost data from a rural cancer registry in Barshi and will be publishing this information in the near future. The Barshi Cancer Registry covers a much smaller population (about 400,000 inhabitants) than the Mumbai Cancer Registry; however, its coverage area (3713 square kilometers) is about three times larger than Mumbai's coverage area, including its satellite registries. It is important to note that the cost of operating rural registries may be higher than urban registries because of the need to employ different types of data collection approaches, including home visits, to accurately register cancer cases [27].

The Mumbai Cancer Registry has played a leading role in cancer registration in India by building a high-quality data repository for cancer research. The registry produces descriptive epidemiology-based statistics, including time trends and geographical patterns of incidence rates, which are useful for planning and evaluation, as well as the generation of hypotheses. The Mumbai Cancer Registry has performed several research studies based on the cancer registry data collection framework. The economic evaluation presented in this study confirm the Mumbai Cancer Registry as a premier organization that is able to produce high-quality data in an efficient manner. The regular use of registry data, such as the high-quality data produced by the Mumbai Cancer Registry, is a significant part of long-term sustainability. Lessons learned from this study can inform the planning and organization of centralized and satellite cancer registries to collect expanded cancer incidence and mortality data. The cost data collected from Mumbai and satellite registries can be broadly generalized across the Indian subcontinent with the caveat of the Indian subcontinent's heterogeneity.

## 6. Conclusion

In middle-income countries like India, where financial resources are limited, the operational framework provided by the Mumbai and satellite registries can serve as a model for expanding data collection to include more representative populations. Centralization of certain registry activities with high fixed costs—especially administration costs—can lead to economies of scale and result in efficient use of limited resources. To ensure high-quality data, the data collection activities can be decentralized, but require local expert advice and supervision. Finally, successful cancer registration activities require the collaboration of multiple stakeholders, including funders, managers, cancer registry experts, and researchers.

## Abbreviations

| | |
|---|---|
| **CDC** | Centers for Disease Control and Prevention |
| **IACR** | International Association of Cancer Registries |
| **ICMR** | Indian Council of Medical Research |
| ***IntRegCosting Tool*** | International Registry Costing Tool |
| **NCDIR-NCRP** | National Center for Disease Informatics and Research-National Cancer Registry Program |

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## Appendix A

**Table A1**

Mumbai Cancer Registry Combined Total Cost per Case by Activity, 2014–2015.

| Activity | Cost per case (Indian rupees) |
|---|---|
| Data collection/abstraction | 106.51 |
| Administration | 31.53 |
| Research or other activities | 27.99 |
| Database management | 21.18 |
| Quality assurance and improvement | 8.40 |
| Analyzing data and generating reports | 6.31 |
| Death certificated clearance | 6.16 |
| Information technology support | 5.73 |
| Management | 4.93 |
| Training of registry staff | 4.66 |
| Developing analytic files | 2.51 |
| Training of others by registry staff | 0.05 |

*Notes*: The cost per case by activity includes all resources expended by Mumbai and the satellite registries. In 2014, 1 US dollar = 60 Indian rupees.
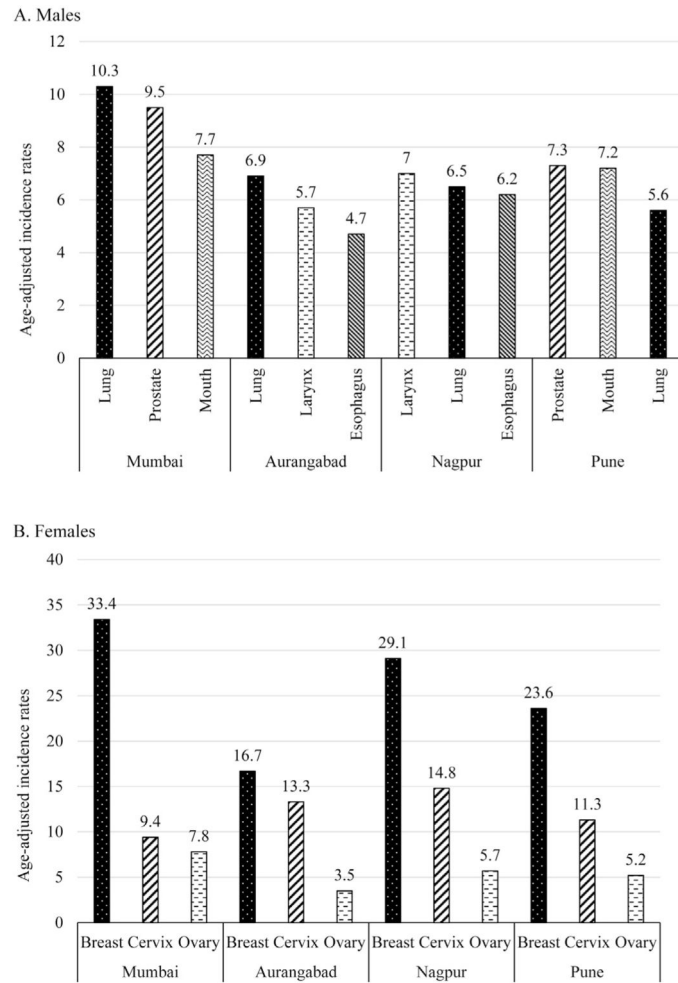
**Fig. 1.**

Top Three Age-Adjusted Incidence Rates per 100,000 Individuals by Registry.

A. Males

*Notes*: Incident rates for Greater Mumbai 2011, Aurangabad annual average 2005–2009, Nagpur annual average 2005–2009, and Pune annual average 2006–2010. Mouth includes the oral cavity and pharynx.
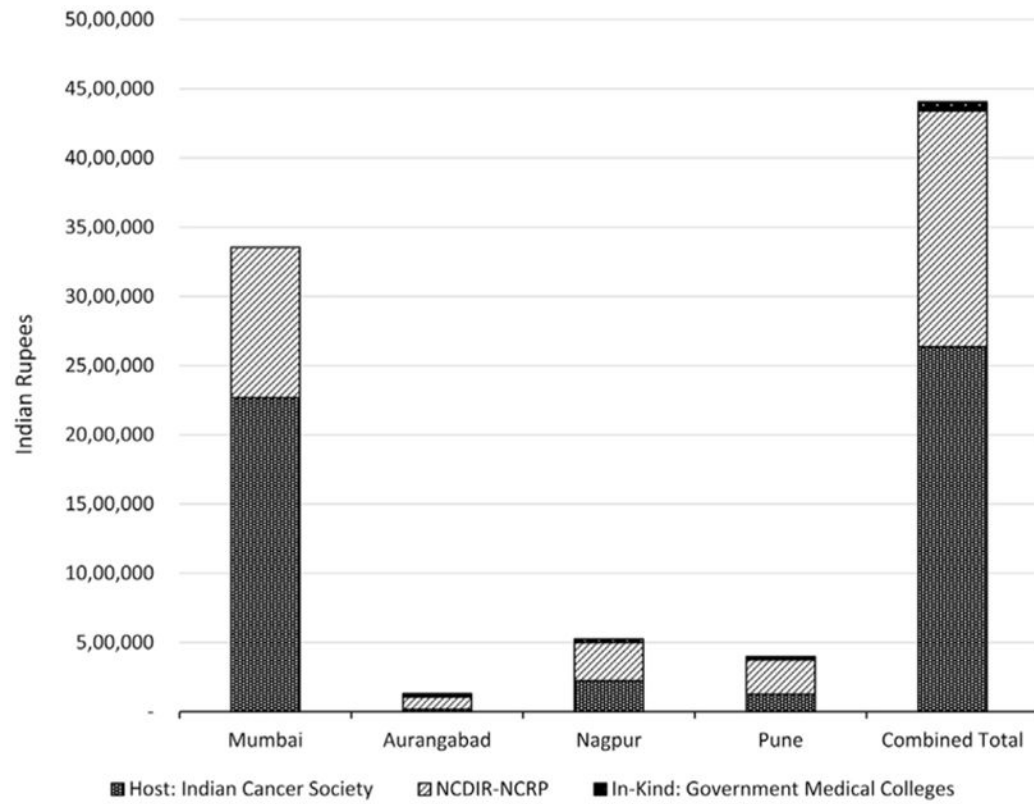
B. Females

*Note*: Incident rates for Greater Mumbai 2011, Aurangabad annual average 2005–2009, Nagpur annual average 2005–2009, and Pune annual average 2006–2010. Mouth includes the oral cavity and pharynx.

**Fig. 2.**
Mumbai Cancer Registry and Satellite Registries' Resources by Source, 2014–2015.
Notes: In 2014, 1 US dollar = 60 Indian rupees. NCDIR-NCRP = National Center for
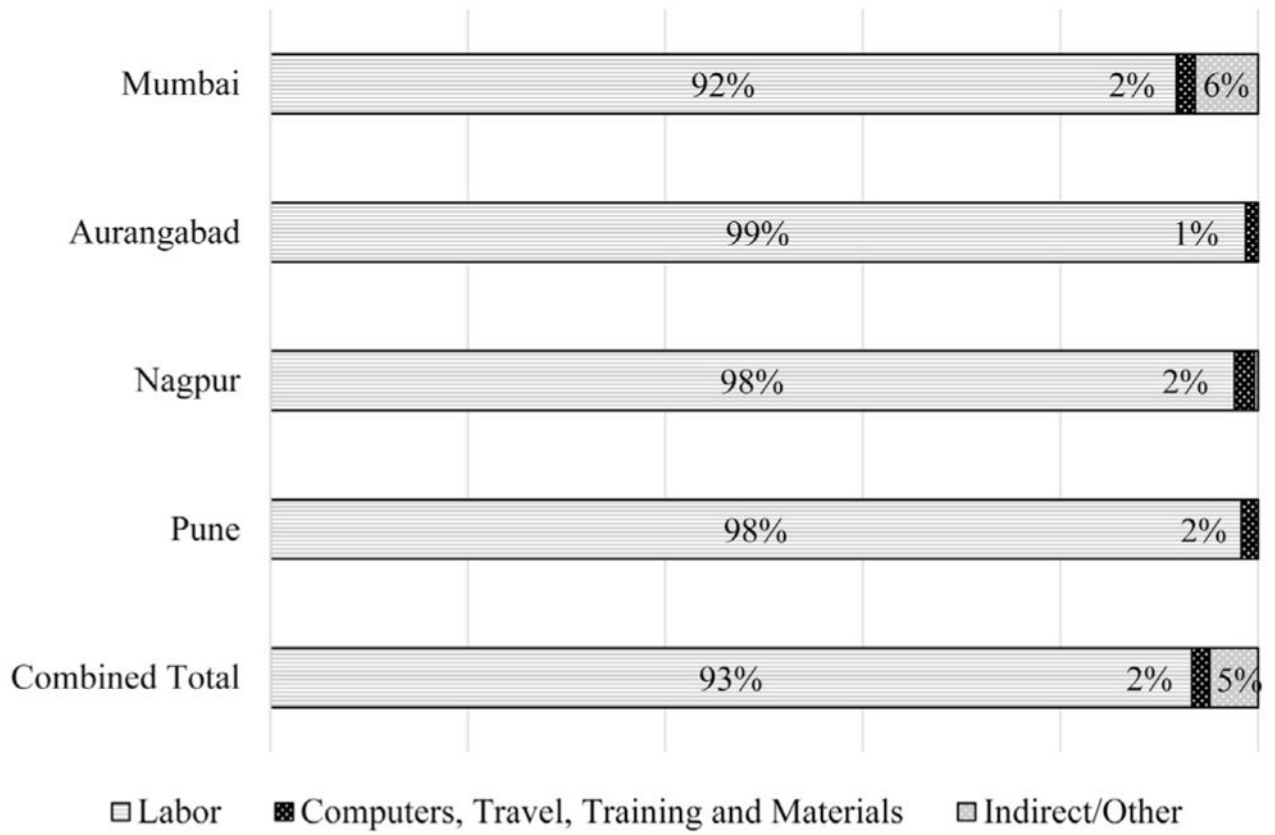Disease Informatics and Research-National Cancer Registry Program.

**Fig. 3.**
Mumbai Cancer Registry and Satellite Registries' Percent Resources by Budget Category, 2014–2015.
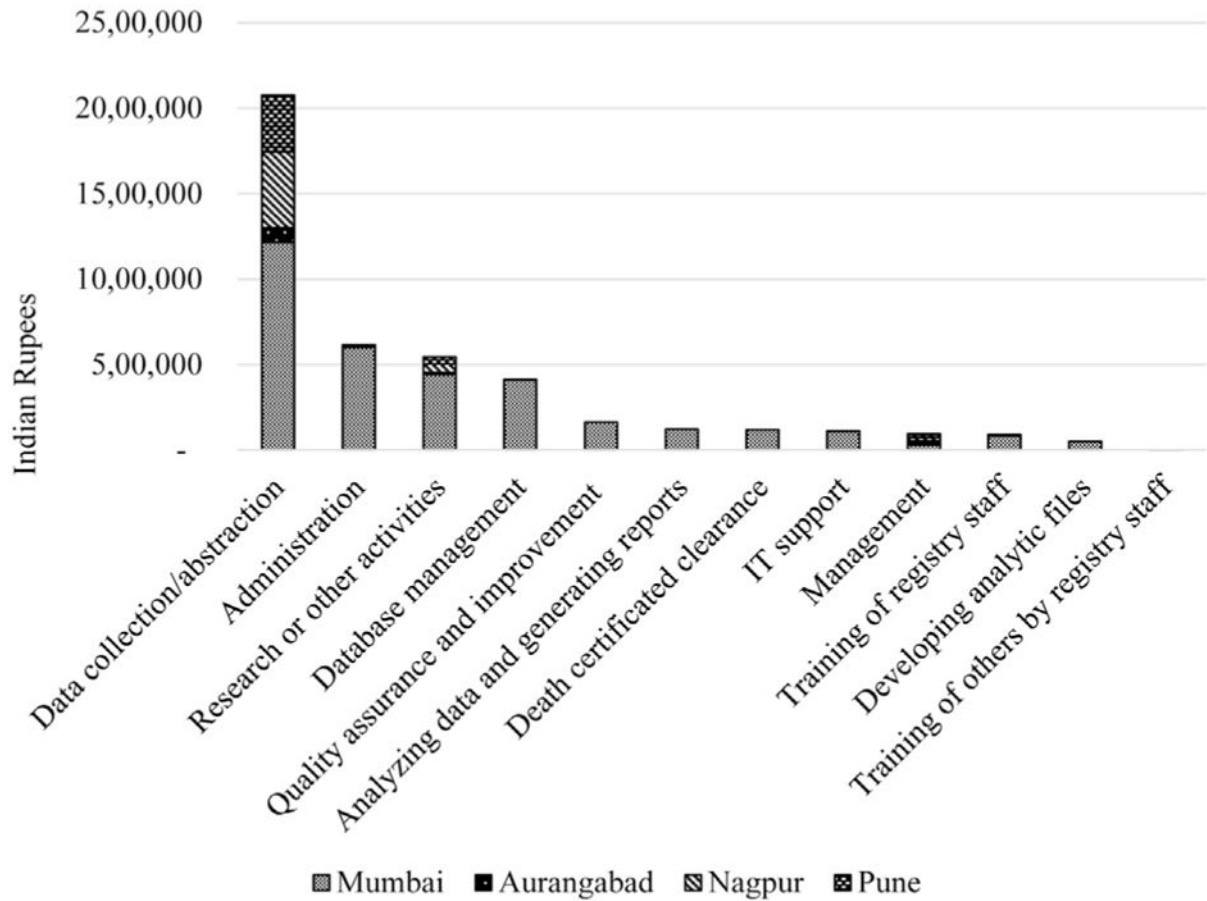
**Fig. 4.**
Mumbai Cancer Registry and Satellite Registries' Resources by Activity, 2014–2015.
*Notes*: The bottom bars indicates activities performed by the Mumbai registry, and all other bars represent activities performed by the satellite registries. In 2014, 1 US dollar = 60 Indian rupees.

**Table 1**

Comparison of the Basic Characteristics of the Mumbai and Satellite Registries, 2012.

|  | Mumbai | Pune | Nagpur | Aurangabad |
|---|---|---|---|---|
| Cancer Cases | 13,383 | 3120 | 2351 | 631 |
| Population | 11,980,000 | 2,538,000 | 2,052,000 | 873,311 |
| Coverage Area (sq. km.) | 603 | 344 | 237 | 50 |

*Notes*: The 2012 cancer incident cases, population within the registry coverage area, and coverage area in square kilometers were provided by the Mumbai Cancer Registry. The Mumbai Cancer Registry serves as the central coordinating entity for the satellite registries; the satellite registries are affiliated registries that perform certain core activities (e.g., data abstraction).