

Costs and Resources Used by Population-based Cancer Registries in the US-Affiliated Pacific Islands

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Abstract

Background: The costs of cancer registration have previously been estimated for registries in the continental United States and many international registries; however, to date, there has been no economic assessment of population-based registries in the US-Affiliated Pacific Islands. This study estimates the costs and factors affecting the operations of US-Affiliated Pacific Island population-based cancer registries.

Methods: The web-based International Registry Costing Tool¹ was used to collect costs, resources used, cancer cases processed, and other registry characteristics from the Pacific Regional Central Cancer Registry (PRCCR), Federated States of Micronesia National Cancer Registry, and nine satellite jurisdictional registries within the US Pacific Islands. The registries provided data on costs for June 30, 2016–June 29, 2017, and cases processed during 2014.

Results: Local host institutions provided a vital source of support for US-Affiliated Pacific Islands registries, covering substantial fixed costs, such as management and overhead. The cost per cancer case processed had an almost tenfold variation across registries, with the average total cost per case of about \$1,413. The average cost per inhabitant in the US-Affiliated Pacific Islands was about \$1.77 per person.

Discussion: The challenges of collecting data from dispersed populations spread across multiple islands of the US-Affiliated Pacific Islands are likely leading factors driving the magnitude of the registries' cost per case. The economic information from this study provides a valuable source of activity-based cost data that can both help guide cancer control initiatives and help registries improve operations and efficiency.

Keywords

Cancer registries, costing, economic evaluation, cancer control, Pacific Islands

Introduction

The US-Affiliated Pacific Islands (USAPI), which comprises three Flag Territories (ie, the Territory of American Samoa, the Territory of Guam, and the Commonwealth of the Northern Mariana Islands) and three Freely Associated States (ie, the Federated States of Micronesia, the Republic of the Marshall Islands, and the Republic of Palau), are facing a rising burden of noncommunicable diseases (NCDs), such as cancer, as a consequence of improved prevention and treatment of infectious diseases leading to improved life expectancy and an aging population.² Furthermore, westernization of culture in the USAPI has driven engagement in unhealthy habits. Tobacco and alcohol consumption, diminishing physical activity, and altered dietary patterns, including sugar-sweetened beverages, imported cereals, and imported fatty meat, are all heightened risk factors that have affected the Pacific region's growing NCD burden.³

Cancer surveillance provides critical information on cancer incidence and trends that decision makers can use to monitor the burden of disease, as well as develop and evaluate targeted cancer prevention and control interventions at local and national levels. The US government's commitment to collecting timely, complete, and high-quality cancer data was affirmed through the 1992 Cancer Registries Amendment Act, which authorized the US Centers for Disease Control and Prevention (CDC) to establish and administer the National Program of Cancer Registries (NPCR).⁴ The CDC financially supports and provides technical assistance and guidance to central population-based cancer registries established in 46 states, the District of Columbia, Puerto Rico, the US Virgin Islands, and the USAPI. The registries provide information on new cancer cases, including type, stage, and location, along with treatment and outcomes.⁵

The Cancer Council of the Pacific Islands (CCPI), which includes regional physician leaders, public health administrators, and comprehensive cancer control program coordinators, established the Pacific Regional Central Cancer Registry (PRCCR) in 2007 in response to the lack of high-quality data collection in the USAPI region, and to improve efforts to combat the rising rates of NCDs.⁶ The CCPI serves as the advisory board to the registry and guides efforts to customize specific data fields and reports that can be used towards the needs of the USAPI region.⁶ The PRCCR is the central administrative hub for multiple population-based cancer registries across jurisdictions within the USAPI. Although cancer registries that produce high-quality cancer data cover most of the US population, the USAPI faces many unique challenges in monitoring the Pacific region's burden of cancer. With a diverse population of around 460,000, the region covers fewer people than the smallest US state, but twice the geographic area of the continent.⁶ The USAPI region faces limited resources,⁷ and the health care infrastructure, capacity, and resource availability vary widely throughout the jurisdictions and represent major structural barriers to diagnosing cancer cases early, providing in-jurisdiction treatment, and implementing cancer control efforts.⁸ Individuals living on remote islands face further barriers to accessing high-quality care because many must travel long distances by boat to reach primary care or treatment centers.⁸ Although no analysis has been done, the CCPI has presumed that rates of cancer in the USAPI may be underreported in light of inconsistent screening and other barriers.⁸

Previous studies have estimated the costs incurred by NPCR registries along with the internal and external factors that affect registry operations and costs.⁹⁻¹¹ Further studies improved the costing methodology from the NPCR study to estimate the costs of international population-based cancer registries of various designs and locations, including island regions and low-income settings.^{12,13} No study has been conducted on the specific economic costs incurred by central and jurisdictional cancer registries located in the USAPI, which has larger geographic disparities compared to previously studied island regions. One needs to know the true cost of cancer registration in the USAPI region to assess efficiencies in the data collection approach and the overall registry structure. We estimate the cost per cancer case of individual population-based cancer registries and overall PRCCR, and identify potential factors that can affect the cost per case and variation between registries.

Methods

Participating Registries and Reporting Structure

The 11 registries located within the USAPI were selected to participate in the costing study to help guide registry leaders and decision makers on the overall and individual factors facing cancer surveillance in the USAPI region. The PRCCR, as the central administrator of cancer registries in the USAPI, oversees and receives data on cancer cases collected by the jurisdictional registries. Although the University of Hawai'i serves as the host

institution for the central registry and is responsible for overall administration, each registry is located within the jurisdiction's Ministry or Department of Health, Division of Public Health, Non-Communicable Disease Bureau, or Branch. The largest registry, Guam Cancer Registry, is based at the University of Guam with support from the Cancer Research Center of Guam. The registries cover a range of populations, from 6,616 inhabitants under the Kosrae State Registry in Federated States of Micronesia (FSM) to 159,358 inhabitants covered by the Guam Cancer Registry. The registries cover a large geographic area throughout the Pacific Ocean, as shown in Figure 1. Individually, the registries cover areas as small as 110 square kilometers in Kosrae to more than 7,000 square kilometers under the FSM National Cancer Registry. Both the PRCCR-Central Cancer Registry and the FSM National Cancer Registry do not collect or process cancer cases, and the remainder of the registries each processed less than 90 cancer cases during the reporting year, with the exception of Guam, which processed 289 cancer cases.

The reporting structure of cancer surveillance operations in the USAPI is presented in Figure 2. Each jurisdictional registry is population-based and functions as a small central registry by consolidating data from a variety of data reporting sources, including out-of-country hospitals, before sending the case to the PRCCR. Each individual jurisdiction manages and performs their own cancer case data collection and entry to localize the process and to support local monitoring and program initiatives in both the public health and curative or hospital sectors. Each



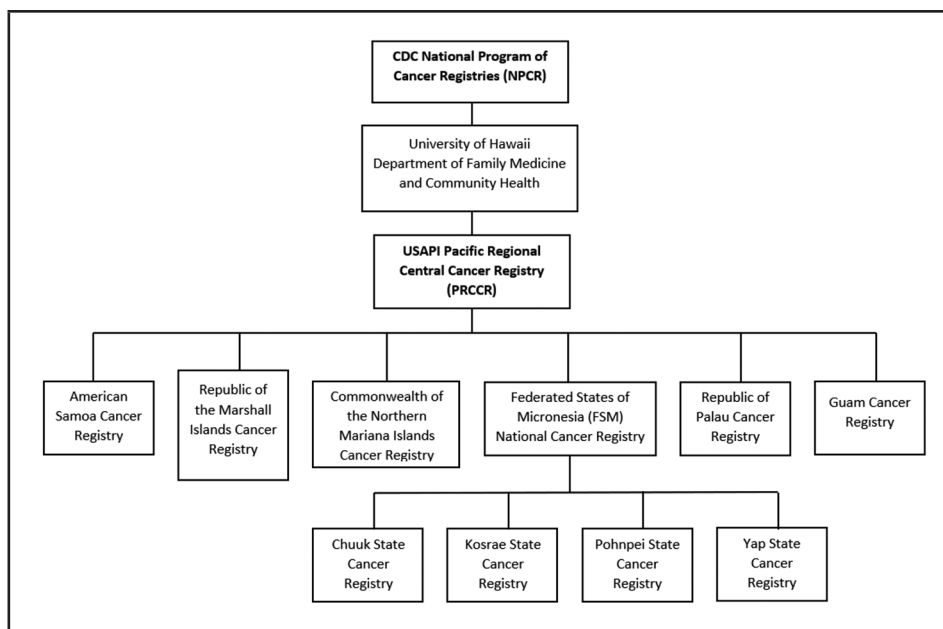


Figure 2. Structure of the US-Affiliated Pacific Islands' Central and Jurisdictional Registries

Notes: PRCCR and FSM National Cancer Registry do not perform data collection directly from original sources; FSM collects cancer cases from 4 state registries within the FSM region, and PRCCR collects cancer cases from all jurisdictional registries.

jurisdictional registry performs their own case ascertainment, data abstraction, editing, death clearance, and follow-up. Jurisdictional registries use CDC-customized reports in Abstract Plus to support efforts to tailor the reporting to individual registry needs.¹⁴ Cases collected by each of the jurisdictional registries are reported to the PRCCR through WebPlus¹⁵ software (CDC-developed software provided at no cost). For the FSM, the National Cancer Registry serves as the intermediary, which performs additional data checks for the state registries of Chuuk, Kosrae, Pohnpei, and Yap within the FSM. FSM has a unique structure compared to the other jurisdictional registries in that the state registries do not submit cases directly to the PRCCR. After the additional data checks, including visual editing and consolidation, FSM transmits cases from the 4 states to the PRCCR. Additional roles of the jurisdictional registries include communication with vital statistics, hospitals, off-island referral offices, and other data sources. Registrars participate in local meetings for comprehensive cancer control (CCC) and NCD working groups and in regional cancer control planning, regional training for software usage, report writing, and cancer staging. The registries work with the University of Hawai'i and CDC to implement new software and to receive ongoing technical assistance and guidance.

Main activities performed by PRCCR include staff trainings, implementing new processes at jurisdictional registries, oversight of local data processes, implementing systems for case identification and cancer reporting in USAPI, building capacity, developing cancer registration systems, and linking individual jurisdictional registries to cancer and NCD control efforts to

support public health initiatives. PRCCR monitors overall trends and cancer burden and guides the USAPI health officials on the appropriate use of cancer data. The PRCCR compiles the cancer data collected by jurisdictional registries and develops reports that are submitted to CDC, jurisdictions, USAPI regional leadership, other US Health and Human Services funding agencies, and other stakeholders and partners, including international partners, such as the World Health Organization (WHO) and the Pacific Community.

Cost Data Collection Approach

The PRCCR used the CDC's web-based International Registry Costing Tool¹ to assess individual island and overall registry costs and resources used. The *IntRegCosting Tool*¹ is web-based data collection and analytic tool where registry staff can directly input information into various modules relating to registry characteristics, resource use and costs and will receive instant summary reports showing outputs of interest to the registry, such as the cost per case results. The tool was initially developed for US cancer registries in the NPCR and was pilot tested among US states and international registries by using an Excel-based version.^{9,13} The PRCCR is the first US-affiliated registry to use the web-based tool since improvements were implemented to streamline the cost collection process. The web tool consists of 10 data collection modules that collect registry characteristics by using an activity-based costing approach. The data collection modules included registry background information, funding sources, data collection approach, registry personnel, personnel activities, other personnel (eg, consultants), computers, travel,

training, and other materials, software licensing, overhead or indirect costs, and narrative feedback. Drop-down boxes allowed registries to allocate specific expenses and labor hours across a wide range of cancer registry activities. All resources were allocated to specific cancer registry activities, which included over 30 registry functions, such as management, training, data collection, data entry, validation, database management, quality control, IT support, and other advanced activities, such as production of materials to support public health functions, research studies funded by the National Cancer Institute, or publications. Registry staff entered the percentage of their overall time that was spent performing the activities, which was used to determine the distribution of their salary allocated across the registry functions. Both actual costs through funds and donations were considered in the calculation of the overall registry cost.

After a series of training webinars and an in-person meeting with the jurisdictional cancer registrars, the PRCCR used a worksheet to collect information from each jurisdictional registry. To simplify the data collection, the worksheet used by the jurisdictional registries was an Excel-based replica of the *IntRegCosting Tool* modules. Each jurisdiction entered details into the worksheet for their registry and then submitted to the PRCCR for review and confirmation. The PRCCR staff then entered each registry's detailed information from the worksheets into the web-based costing tool across budget categories related to both labor and nonlabor costs and resources used, including donations or in-kind contributions. A user's guide and ongoing technical assistance were provided to the registry to support their data inputs. Because the USAPI's structure includes multiple islands and jurisdictional registries, we collected and entered cost data separately for each location to isolate the cost per jurisdiction before assessing the cost of the full registry. Costs were collected for a 1-year time frame: June 30, 2016 through June 29, 2017. The registries provided the number of cancer cases that were reported during 2014. Costs were reported for all 11 registries, although only the registries that performed data collection (all except PRCCR and FSM) reported cancer cases.

After the PRCCR registry completed the data inputs, the web tool ensured that all quality checks had been satisfied through a series of quality validations. The validations helped confirm that all required information was entered into the data modules, and that the registries' data passed quality checkpoints, such as percentages adding to 100 percent. Following the registries' confirmation of data, researchers also reviewed the data to ensure completeness.

The *IntRegCosting Tool*¹ contains a built-in data analytic tool that calculated the registry's cost results. Using the cost and resource use data provided by the USAPI registries, the analytic tool produced summary reports that estimated the registry's high- and low-cost activities, resources per budget category, resources by source, and cost per cancer case and inhabitant.

Resources allocated to the overhead data module, such as for rent or utilities, were prorated across the distribution of the other cancer registry activities, as these indirect costs were in support of overall registry operations. We present the results based on data entered into the web-based tool.

Results

Registry Characteristics and Incidence Rates

Characteristics of the 11 USAPI registries are presented in Table 1. In 2016–2017, the registries each had at least 1 full-time equivalent, with PRCCR-Central having fewer than 3 full-time equivalents, including the staff based in Honolulu at the University of Hawai'i. Cancer is a reportable disease, by law, in all USAPI registries, which aligns with US policy; and all actively enforce cancer reporting to the jurisdictional registry, in which the registry is able to use the legislation to mandate access to cancer cases. Registries that collect and process data have at least 3 total data sources, with Yap having 7 total sources. None of the registries perform regular active follow-up on all cases as they are staffed by one person to accomplish all activities. However, all registries perform death clearance, along with the collection of *in situ* cancers of the breast, cervix, vagina, and anus, as well as melanoma and nonmelanoma skin cancers. Because the smaller jurisdictional registries are housed within a hospital's medical records department or have an excellent reporting relationship, the registrars receive new information, update their database, and provide updates to the PRCCR.

The age-standardized incidence rates for the top 5 cancers across all USAPI registries are reported by sex in Figure 3. Among females, breast cancer had the highest annual, age-standardized incidence rate from 2007 to 2014, with almost 52 new cases per 100,000 population. This is followed by lung and bronchus cancer with about 22 new cases per 100,000 per year, then uterus, cervical, and colon and rectum cancers. Among males, prostate cancer has the highest age-standardized annual incidence rate, with 57 new cases per 100,000 population, followed by lung and bronchus cancers with 53 new cases per 100,000 population. Colon and rectum cancers have about half the incidence rate of lung and bronchus, followed by liver cancer and leukemia.

Registry Cost Results

Figure 4 presents the sources of support for registry operations, including through actual funds that support registry costs and donated resources, such as office space. Registries receive their main source of financial support via sub-awards by the University of Hawai'i through funding from the NPCR. The sub-awards go towards the central registries, along with each of the jurisdictional registries for the financing of personnel, and is often used for the financing of computers, travel, training, and other materials. PRCCR-Central is entirely supported by the University of Hawai'i, which serves as its host institution,

Table 1. Characteristics of the US-Affiliated Pacific Islands Population-based Cancer Registries											
	American Samoa	Republic of the Marshall Islands	Commonwealth of the Northern Mariana Islands	PRCCR - Central	Republic of Palau	FSM National	Pohnpei State, FSM	Chuuk State, FSM	Kosrae State, FSM	Yap State, FSM	Guam
Date established	2007	2007	2007	2007	2007	2007	2007	2007	2007	2007	2007
Host institution type	Health Dept.	Health Dept.	Health Dept.	University	Health Dept.	Health Dept.	Health Dept.	Health Dept.	Health Dept.	Health Dept.	University
Population covered	55,519	53,158	53,883	0	20,518	0	35,981	48,651	6,616	11,376	159,358
Area covered (sq KM)	199	181	464	2,550	465	7,006	346	701	110	118	540
Cancer cases processed (2014)	7	67	82	0	27	0	46	7	5	29	289
Full-time equivalents	1	1	1	2.84	1.6	1	1	1	1	1	2.52
Reportable disease	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
If yes, actively enforced?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total sources	3	5	3	11	3	1	6	3	3	7	6
Performs active follow-up	N	N	N	N	N	N	N	N	N	N	N
Performs death clearance	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Collects <i>in situ</i> cancers	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Collects melanoma skin cancers	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Collects nonmelanoma skin cancers	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y

Notes: Cancer cases correspond to the number of cases collected and processed during 2014. Information on other factors and characteristics were reported by cancer registry representatives and correspond to the year of cost data reported, June 30, 2016–June 29, 2017. PRCCR Central Registry and FSM National Cancer Registry do not directly perform data collection; thus, cancer cases processed is 0 for both registries. All registries collect *in situ* uterine cervix, vagina, and anal cancers to monitor long-term impacts of the human papillomavirus vaccination programs. FSM, Federated States of Micronesia; PRCCR, Pacific Regional Central Cancer Registry.

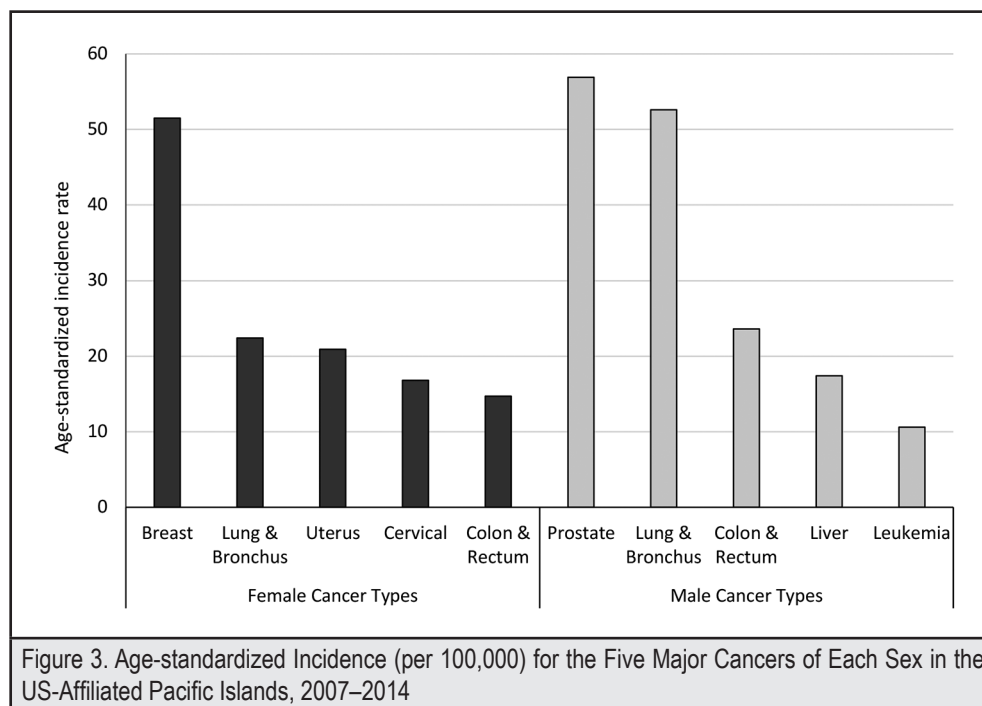


Figure 3. Age-standardized Incidence (per 100,000) for the Five Major Cancers of Each Sex in the US-Affiliated Pacific Islands, 2007–2014

Source: Pacific Regional Central Cancer Registry (PRCCR), 2007–2014.

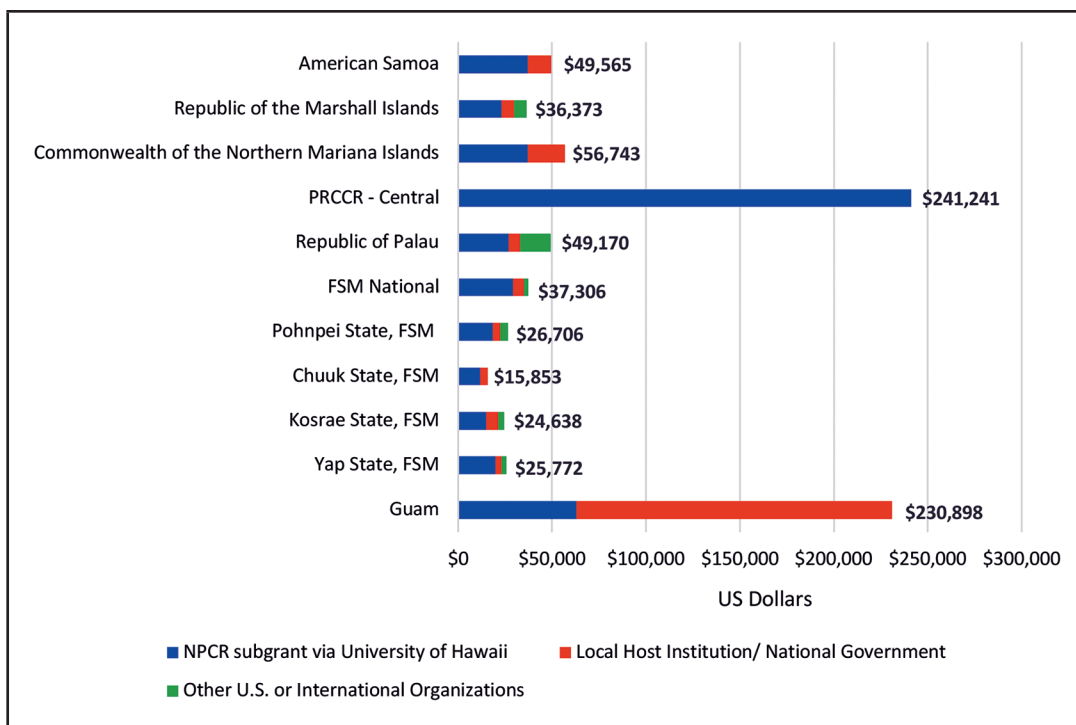


Figure 4. US-Affiliated Pacific Islands Registries' Resources by Source

Notes: Costs were reported by cancer registry representatives for the reporting year June 30, 2016–June 29, 2017; PRCCR-Central and FSM National do not directly perform data collection but received funding to perform administrative duties, training, and other essential central registry functions. PRCCR-Central is entirely funded via grant support from the University of Hawai'i. FSM, Federated States of Micronesia; PRCCR, Pacific Regional Central Cancer Registry; RMI, Republic of the Marshall Islands.

as well as its *bona fide* agent for the region's NPCR funding. Support from the registries' local host institutions largely supports registries' space, utilities, minimal IT support, and other administrative resources. The University of Guam provided the majority of support for the cancer registry in Guam, which also received a portion of their funding from the University of Hawai'i, through a sub-award of the NPCR funding. In contrast to the other registries, the registry in Palau received significant funding through international organizations, such as the New Zealand Agency for International Development, Japan International Cooperation Agency, and WHO.

Figure 5 presents the distribution of total USAPI registries' resources by budget category. About 55% of all the resources went towards registry personnel, through employee salaries. Registrar salaries ranged from \$20,000 to \$35,000 in most of the jurisdictions, and as low as \$11,000 in the FSM States. The second largest portion of resources went toward overhead, representing about 22% of the overall registries' resources. Other personnel, such as consultants, represented about 14% of the registries' resources, whereas computers, travel, training, and other materials represented 9% and software less than 1%.

The distribution of total registries' resources by cancer registry activity, including donations, are presented in Figure 6. Management had the highest level of resources incurred, (around \$166,000). Public health, contributing data to research projects, and other activities had around \$160,000 incurred, which largely included manually linking records to other databases. The third largest activity was data collection and abstraction (around \$141,000). With the exception of Guam, which has a cancer research center partially supported by NCI funding, all jurisdictional registry data products and outputs were used primarily to improve public health outreach, education, screening services, and to guide prioritization of other local programs and health services to support cancer patients and their families.

Table 2 presents each of the registries' cost per cancer case processed and cost per inhabitant, with the exception of the PRCCR and FSM National Registry. The largest registry, located in Guam, had a cost per case of nearly \$800 and cost about \$1.45 per inhabitant in its coverage area. The registry with the highest cost per case was the American Samoa Cancer Registry, at about \$7,080 per cancer case processed, whereas the registry with the lowest cost per case was the Cancer Registry of RMI, which cost about \$476 per case. Altogether, the registries processed 559 cancer cases during 2014 and had a cost per case of \$1,413 and a cost per inhabitant of about \$1.77.

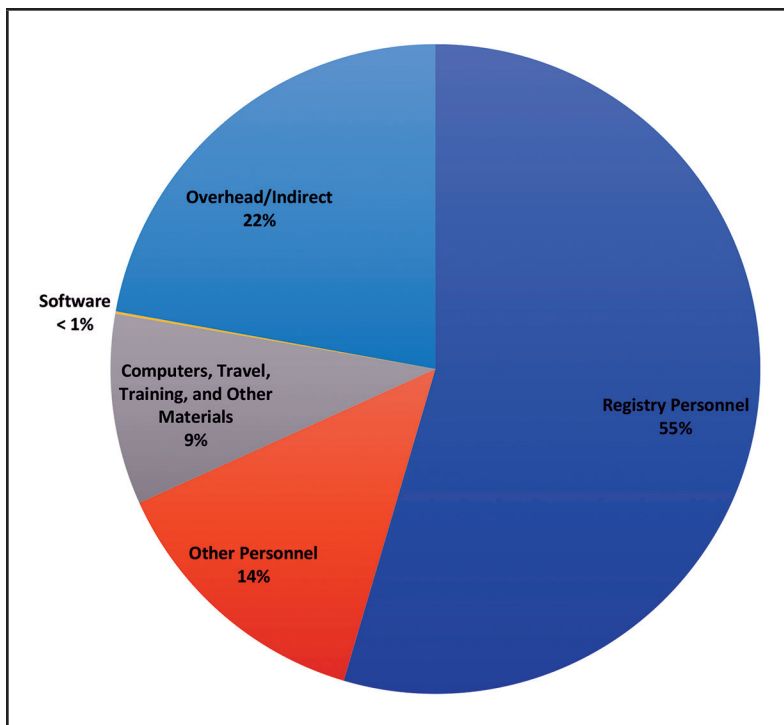


Figure 5. US-Affiliated Pacific Islands Registries' Resources by Budget Category

Notes: Costs were reported by cancer registry representatives for the reporting year June 30, 2016–June 29, 2017. FSM, Federated States of Micronesia; PRCCR, Pacific Regional Central Cancer Registry; RMI, Republic of the Marshall Islands.

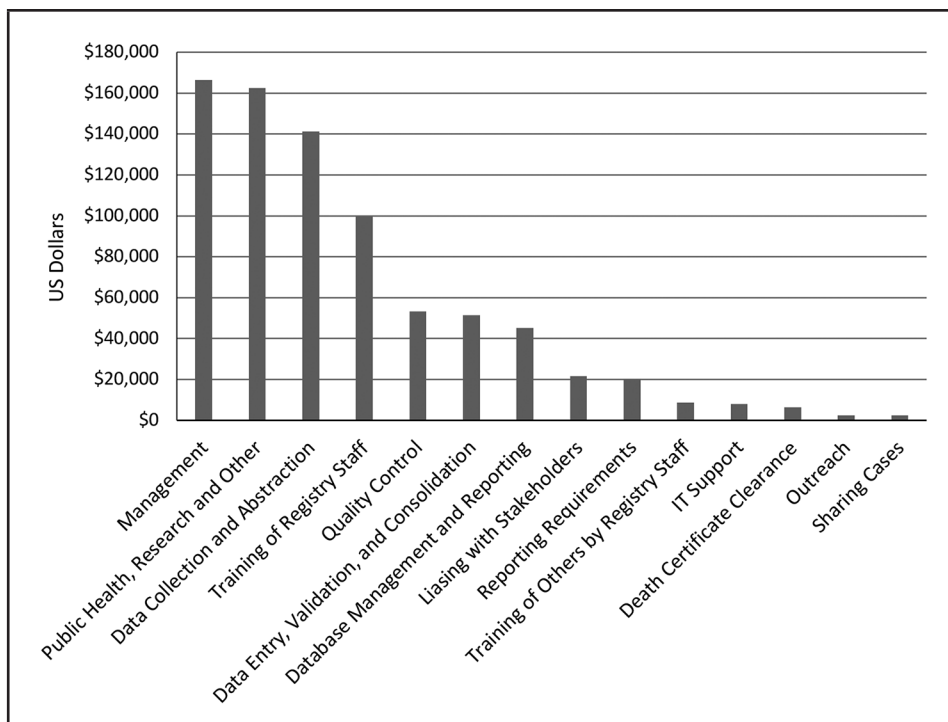


Figure 6. Distribution of Total US-Affiliated Pacific Islands Registries' Resources by Activity

Notes: Costs were reported by cancer registry representatives for the reporting year June 30, 2016–June 29, 2017. The activity "Public Health, Research and Other" is inclusive of traditionally non-core registry operations and largely includes record linkages to other databases, including contributing data to NCI-funded research studies and advanced analysis, publications, and other public health-related efforts.

Table 2. US-Affiliated Pacific Islands Registries' Cost Per Case and Cost Per Inhabitant											
	American Samoa	Republic of the Marshall Islands	Commonwealth of the Northern Mariana Islands	Republic of Palau	FSM					Guam	USAPI Total
					Total	Pohnpei State	Chuuk State	Kosrae State	Yap State		
Cancer Cases	7	67	82	27	87	46	7	5	29	289	559
Inhabitants	55,519	53,158	53,883	20,518	102,624	35,981	48,651	6,616	11,376	159,358	445,060
Cost per Case	\$7,080	\$476	\$692	\$1,713	\$1,497	\$581	\$2,265	\$4,927	\$889	\$799	\$1,413
Cost per Inhabitant	\$0.89	\$0.68	\$1.00	\$2.25	\$1.27	\$0.74	\$0.33	\$3.72	\$2.27	\$1.45	\$1.77

Notes: Cancer cases corresponds to the number of cases collected and processed during 2014. Costs were reported by cancer registry representatives for the reporting year June 30, 2016–June 29, 2017. FSM Total includes the costs for FSM National along with the individual states; USAPI Total includes the costs for PRCCR, FSM National, and each of the jurisdictional registries within the USAPI. FSM, Federated States of Micronesia; PRCCR, Pacific Regional Central Cancer Registry; RMI, Republic of the Marshall Islands; USAPI, US-Affiliated Pacific Islands.

Table 3. Narrative Feedback on Potential Factors Affecting US-Affiliated Pacific Islands Registries' Operations	
Factor	Description
Internal Barriers and Facilitators	
Volume of cases	Low case volume makes it more difficult to achieve economies of scale.
Data abstraction methods	Widely paper-based methods because of a lack of implementing electronic methods.
Quality of data	Lack of complete case reporting in some jurisdictions.
Staff expertise	Technical expertise needed to improve or begin use of more electronic reporting.
Organizational structure	Resources spread across many satellite registries with large administrative resource needs.
External Barriers and Facilitators	
Geographic coverage	Travel and data collection are costly across large geographic area.
Funding	Funding supports improvements in registry capacity and training programs.
IT support and technical assistance	Further technical assistance can improve capabilities in electronic reporting.
Partnerships	Partnerships are crucial for helping synergize efforts and seeking additional resources.

Notes: Narrative feedback received by registries through costing tool or correspondence via email.

Table 3 includes the qualitative data that was collected from the registries through narrative feedback in the costing tool. Registries and the directors noted important factors that they perceived to be barriers or facilitators to their operations and achievement of registry objectives. All registries within the USAPI note their need to improve case completeness, and to achieve more complete staging or treatment information on cancer cases because many are treated abroad. The lack of electronic health records in some jurisdictions means that poorly organized paper records are widely used, which creates inefficiencies and leads to a higher chance of lost records. USAPI registry directors reported that given limited capacity and resources, the USAPI does not plan to prioritize e-reporting until jurisdictions substantially improve their health IT capacity. Consequently, many providers and hospitals in the USAPI are not able to meaningfully use electronic health records or participate in the Promoting Interoperability Program.¹⁶⁻¹⁷ Along with information and communication technology challenges,

the lack of sufficient on-island expertise to work on e-reporting was cited as an area for improvement in registry operations. However, registry directors did not anticipate that this would change anytime soon, given the need to apply current resources and capacity to other pressing health priorities. Many registries also noted the need for additional training and support for registry operations.

Discussion

This is the first study to report detailed costs of cancer registration in the context of the US-Affiliated Pacific Island Region. The results of this web-based cost data collection showed that the total cost per case across all registries was about \$1,413. This cost per case is substantially higher than the average cost per case of US registries that participated in the NPCR evaluation, which was about \$61 per case.¹⁰ The total cost per inhabitant of about \$1.77 was also much higher than the cost per inhabitant

of international cancer registries, in which most had a cost per inhabitant of less than \$0.50.¹² The USAPI likely faces higher costs per case than other registries because of their unique circumstances as island territories.

The burden of surveilling a geographic area almost twice the size of the continental United States requires substantial resources to support a large number of satellite registries. Each registry faces significant fixed costs, including rent for office space and equipment. Furthermore, all registries perform active data abstraction, including Guam's routine communication with hospitals and free-standing clinics to acquire information. Data abstraction is almost entirely paper-based in most jurisdictions, which contributes to inefficiencies. Records from out-of-country cancer care are actively sought and can take up to 6 months in some locales. Travel throughout jurisdictions covering a large geographic area makes data collection resource-intensive, and leads to significant expenses for annual meetings or training on other islands. The geography of the Pacific islands presents many unique challenges; most previously studied registries were single entities that spread resources across large volumes of cancer cases.

Another primary factor driving the higher cost per case among the USAPI registries is likely the small number of cancer cases processed within the USAPI. A previous study showed case volume to be significantly associated with a cancer registry's cost per case.¹⁰ In the US NPCR study, in which the majority of registries processed at least 10,000 cases annually, registries that processed a larger volume of cases were able to achieve economies of scale by spreading fixed and semivariable costs across a set number of cases. As the USAPI registries altogether cover a smaller population than NPCR registries, and processed less than 600 cancer cases annually across 11 individual registries, the high cost per cancer case processed in the USAPI is aligned with expectations. This factor is further evident in the high cost per case of the American Samoa registry, which like Chuuk, processed a small number of cancer cases because of personnel challenges noted by the PRCCR staff.

The quality of the data collected has also been shown to be an important factor in the cost per case of cancer registries, with NPCR registries that produce higher quality data experiencing a significantly lower cost per case.¹⁰ Per the internal report from CDC to PRCCR of a routine NPCR data quality audit of 2013 cases, coding was correctly supported by text fields with 96% concordance. However, cancer registries in the USAPI do not meet some of the other quality thresholds needed for inclusion in the *Cancer Incidence in Five Continents* publication,¹⁸ and face many limitations in their processes for collecting cancer data.⁸ Cancer cases are likely underreported in the USAPI, as there is lack of complete case reporting in some jurisdictions because of individuals on remote islands who are unable to or avoid seeking care, or patients with high personal wealth choosing to travel elsewhere for diagnosis and treatment.⁸

Local capacity building, more intensive training, and increased technical assistance are areas that registry directors and other stakeholders may consider when seeking to improve efficiency in registry operations and reduce structural barriers to cancer registration.¹³ The registries noted that through the efforts of the Pacific Island Health Officers Association, CDC, the Association of State and Territorial Health Officers, and other funders, resources have been allocated in the USAPI in the past 4 years to strengthen their overall capacity for surveillance of both chronic and infectious disease. The registries also indicated that on-site technical assistance and training for strengthening the civil registration and vital status functions were perceived as viable solutions to improve the quality of data and improvement of registry operations. Furthermore, the USAPI registries have already formed partnerships with the International Agency for Research on Cancer and the International Association of Cancer Registries in the development of the WHO Pacific Hub and will continue to explore opportunities to collaborate and synergize efforts to improve efficiencies in the USAPI Cancer Registries.

A limitation of this study is the estimation of indirect costs. As many costs relating to overhead or equipment used were provided by a host institution without a direct transfer of cash from the registry, many web-tool users estimated the market value of their office space and administrative costs. These costs were important to collect as part of evaluating the overall economic costs of cancer registration, which include both donations and expenses. Potential errors were minimized through the use of market value or exact amounts provided directly by the local host institutions. In addition, all values were reviewed by researchers for their plausibility. Another limitation of this study is the retrospective nature of the cost data collection. Retrospective data collection can lead to recall error; the reliability of exact costs and factors provided may depend on the registries' record-keeping practices, or in instances of donations, recall of exactly what was provided during the reporting year.

Strengths of this study include the use of a validated web-based costing tool that collects detailed activity-based costs on all aspects of cancer registry operations. As the costing tool included details of important indirect costs and in-kind contributions, the results in this study represent the true economic costs of running the registries. This study sought information on costs and factors directly from registry representatives and allowed each staff member to report the allocation of their time across specific registry activities. Therefore, this study provides a realistic account of what the registries are facing. The cost per case varied significantly across registries in this study; thus, future assessments could review causes of this variation to identify lessons learned and potential options for improving efficiency and reducing registries' cost per case.

Conclusions

This study provides needed information for decision makers to understand sources of financial support for registries in the USAPI, proportions of resources allocated to various registry activities, and factors that may be influencing the high cost per case experienced by USAPI registries. Registry leaders and other decision makers can use the cost per case and cost per inhabitant figures from this study to identify areas for potential operational improvement and to inform efforts to align cost-drivers and quality of registration activities for USAPI registries with those of other NPCR registries.

Conflict of Interest Disclosure Statement

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