



The cost of cancer registry operations: Impact of volume on cost per case for core and enhanced registry activities



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ABSTRACT

Background: Cancer registration data is vital for creating evidence-based policies and interventions. Quantifying the resources needed for cancer registration activities and identifying potential efficiencies are critically important to ensure sustainability of cancer registry operations.

Methods: Using a previously validated web-based cost assessment tool, we collected activity-based cost data and report findings using 3 years of data from 40 National Program of Cancer Registry grantees. We stratified registries by volume: low-volume included fewer than 10,000 cases, medium-volume included 10,000–50,000 cases, and high-volume included >50,000 cases.

Results: Low-volume cancer registries incurred an average of \$93.11 to report a case (without in-kind contributions) compared with \$27.70 incurred by high-volume registries. Across all registries, the highest cost per case was incurred for data collection and abstraction (\$8.33), management (\$6.86), and administration (\$4.99). Low- and medium-volume registries have higher costs than high-volume registries for all key activities.

Conclusions: Some cost differences by volume can be explained by the large fixed costs required for administering and performing registration activities, but other reasons may include the quality of the data initially submitted to the registries from reporting sources such as hospitals and pathology laboratories. Automation or efficiency improvements in data collection can potentially reduce overall costs.

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1. Background

Annually, more than 1.4 million people in the United States are diagnosed with cancer, and these cancer cases are recorded by cancer registries (U.S. Cancer Statistics Working Group, 2013). Cancer registries play a critical role in providing the information needed to develop comprehensive and targeted cancer control interventions to reduce the burden of cancer. Information about cancer incidence is needed to evaluate cancer trends; identify and address cancer disparities; and track progress toward cancer prevention and control goals, such as those established by Healthy People 2020 (U.S. Department of Health and Human Services, 2014).

In 1992, the U.S. Congress passed the Cancer Registries Amendment Act, which authorized the Centers for Disease Control

and Prevention (CDC) to establish the National Program of Cancer Registries (NPCR) and provide financial support and technical assistance to state health departments for the operation of central population-based cancer registries to collect complete, timely, and high quality data on cancer incidence. Currently, the NPCR supports cancer registries in 45 states, the District of Columbia, Puerto Rico, and the Pacific Island jurisdictions (Centers for Disease Control and Prevention, 2015). The NPCR and the Surveillance, Epidemiology and End Results (SEER) Program provide support to cancer registries in all 50 states, covering the entire United States population (National Cancer Institute, 2015). In addition to the federal initiatives, states also provide significant matching funds to support the operations of cancer registries.

Although some prior studies have reported on the cost of cancer registry operations, there has been no systematic assessment of the cost expended on specific activities performed by the registries. A previous study estimated the average cost per case reported by NPCR-funded registries and identified factors that explained state variations (Weir, Berg, Mansley, & Belloni, 2005). However, that

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study underestimated the true cost (with a median cost per case of \$18.43 and range from \$3 to \$230), as state funding and in-kind contributions were not included. Other studies have reported activity-based costs collected from a small number of cancer registries (median cost per case of \$45.84 ranging from \$30 to \$100) though their findings cannot be generalized to the overall U.S. population (Tangka, Subramanian, Cole Beebe, Trebino, & Michaud, 2010; Subramanian, Tangka, Green, Weir, & Michaud, 2009). Identifying the resources required for cancer registration activities and increasing efficiencies is critically important to ensure optimal use of the funding available from federal, state, and in-kind contributions.

The objective of the current study was to estimate the average cost per single cancer case for each key registration activity performed by NPCR-funded registries using more representative data and more complete data than prior studies. Central cancer registries perform a large number of core surveillance (key activities related to collection of cancer incidence data and maintenance of the registry database [Appendix Table A1]), data enhancement, and analysis activities. Previous analyses have observed potential economies of scale in registration operations or noted that further research is needed to understand variations in cost per case across registries (Weir et al., 2005; Tangka et al., 2010). In this study, we stratify registries based on volume to explore the cost per case incurred in each group for specific registration activities. Our findings may help to quantify the resources needed for cancer registration activities, lead to understanding of variations in cost per case for specific activities, and identify approaches that can improve the efficiency of registry operations.

2. Methods

We used a previously developed web-based Cost Assessment Tool (web-CAT) to collect activity-based cost data from the 48 NPCR-funded registries. The NPCR web-CAT was developed using economic evaluation theory and activity-based costing methodology (Anderson, Bowland, Cartwright, & Bassin, 1998; Drummond, Sculpher, Torrance, O'Brien, & Stoddart, 2005; French, Dunlap, Zarkin, McGeary, & McLellan, 1997; Salome, French, Miller, & McLellan, 2003). Details on the web-CAT development and validation have been previously reported (Subramanian et al., 2007; Subramanian, Ekwueme, Gardner, Bapat, & Kramer, 2008). The web-CAT allows for data collection across budget categories, including labor, consultant and contract expenditures, computer software and hardware, travel and training, and administrative or overhead expenses. The NPCR web-CAT includes 10 screens that collect data on various aspects of registry operations: (1) descriptive details on the registry itself, including program type; (2) total expenditures (all funding sources); (3) in-kind contributions; (4) personnel expenditures; (5) personnel activities; (6) consultant/contractor expenditures; (7) computers, travel, training and other expenditures; (8) software expenditures and details on the database management software used by the registry; (9) administrative costs; and (10) factors affecting registry operations (including number of cases reported, records received, data submission formats). In addition, a final screen provided a summary of the data reported by the registry and a confirmation screen allowed the user to submit the data. In addition to introductory information with background on the economic evaluation of the NPCR and general instructions on entering, saving, and submitting data, the user's guide also provided detailed information and instruction for each web-CAT screen.

Registry staff members (often the registry director) were asked to allocate expenditures (including employee time) to various program activities. The cost data was reported retrospectively and

registry staff allocated actual expenditure to specific activities. To ensure that data was standardized across the registries, we offered training webinars, a detailed user's guide with definitions for each activity, and ongoing technical assistance to address any questions about data collection and reporting. The percent time reported was provided by the registry staff and then multiplied by the annual salary (or actually time spent if it is less than 12 months). The cost for each activity was summed up.

Cost data were collected for a 3-year period (program years 2008–2009, 2009–2010, 2010–2011) on registry funding (including in-kind contributions), expenditures, number of cases reported, and factors that might affect the efficiency of operating a central cancer registry. We collected cost data for multiple years to account for variations in registry activities and costs from year to year. In addition, because cases are collected and processed on a continual basis (takes up to two years to collect complete data on a case), we used the number of cases reported during the cost data collection period to calculate the cost per case. This is based on methodology previously used and since cases do not vary dramatically between years, the number reported provide a good approximation of the cases at various stages of completion in any given funding period (Subramanian et al., 2009). Given the two year delay in reporting cancer cases, we used cancer cases diagnosed in 2006, 2007 and 2008 for the program years 2008–2009, 2009–2010, 2010–2011 respectively. In addition, to standardize calculations for cost per case, we limited the cases used in the analysis to in-state cases collected by the registry.

We used a programmatic perspective, taking into account all resources, regardless of funding source, in our activity-based cost assessment. In-kind contributions included nonmonetary assistance and support provided to the registries. In-kind labor contributions include physician consultation to the registry, IT services, and time spent by state administrator to support registry activities while in-kind non-labor contributions include supplies and materials, and office space. Registries reported in-kind contributions directly and also provided the method used for estimating the value of each contribution. Reported methods include internal best estimates, market value, and foundation budget amounts (when resources were allocated to provide goods/services to the cancer registry).

We performed a series of data checks to ensure the accuracy of the data reported by registries. Several of these data checks were automated within the web-CAT (for example, totals of each allocation category sum to 100% and funds expended match expenditure allocated for the fiscal year), which ensured that final submission met key data quality standards. We limited the difference between reported funding and total expenditures allocated to specific activities to within a difference of 5%. We also required reported time spent on activities to total 100% for each registry employee. In cases where a registry used a major contractor, both the registry and the contractor were required to submit data via the web-CAT. To facilitate the aggregation of registry and contractor data and to avoid double counting, reported funding for both the contractor and registry were linked.

Finally, we further validated the data by comparing reported NPCR funding in the web-CAT with funding amounts in CDC records. Each registry-reported number of cancer cases was compared with CDC internal records and United States Cancer Statistics (USCS) cancer cases; these served as guidelines for assessing accuracy, as cases were not expected to match exactly (registries may report additional cases not required by CDC or USCS). Registries reviewed and approved summaries of the validated data following each of the three rounds of data collection.

To create activity-based cost data files, we first allocated costs to specific registry activities by totaling the cost of each registry activity across all budget categories. For example, in terms of

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