



Economic assessment of integrated cancer and cardiovascular registries: The Barbados experience



Tanya N. Martelly^a, Angela M.C. Rose^a, Sujha Subramanian^b, Patrick Edwards^b,
Florence K.L. Tangka^{c,*}, Mona Saraiya^c

^aChronic Disease Research Centre, The University of the West Indies, 'Avalon', Jemmott's Lane, St. Michael, Barbados

^bRTI International, 3040 E. Cornwallis Rd., Research Triangle Park, NC, USA

^cCenters for Disease Control and Prevention, 4770 Buford Hwy., Atlanta, GA, USA

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ABSTRACT

Background: This report describes the resources required to support the integrated approach of the Barbados National Registry for Chronic Non-communicable Diseases (BNR) to non-communicable disease (NCD) case registration, and to identify differences in cost for collecting and maintaining information on cancer and cardiovascular disease (CVD) case registration.

Methods: We used the modified Centers for Disease Control and Prevention's International Registry Costing Tool to collect data from the CVD and cancer registries. We used cancer and CVD cost data for the annual period April 2014 through March 2015 to estimate the total cost and cost per case. We used prospectively collected average annual CVD cases, and for cancer cases we assumed 2 or 3 years are needed for retrospective data collection.

Results: The Ministry of Health provided 56% of the resources for the registries. Labor accounted for over 70% of both registries' budgets, while management and administration, along with data collection and analysis, incurred the highest costs per case. Total variable cost activities related to data collection and analysis were higher for the CVD component (US\$131,297) than the cancer component (US\$58,917). The CVD cost per case (US\$489) was in between the cancer 2-year (US\$382) and the cancer 3-year (US\$573) cost-per-case estimates.

Conclusion: These findings indicate that there are substantial fixed costs related to management and administration of NCD registries. All registries need management and administration support. When registries are combined, management and administration costs can be shared. We project that registries that can share fixed-cost infrastructure are likely to incur a lower total cost per case.

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1. Introduction

The Caribbean Community (CARICOM) has the highest prevalence of non-communicable diseases (NCDs) in the Americas, causing much premature loss of life, lost productivity, and spiraling healthcare costs [1]. It is expected that NCD deaths in this region will increase by 17% over the next 10 years, and predictions for the ensuing two decades include a near tripling of ischemic heart disease and stroke mortality [2]. In response to this epidemic, the CARICOM Heads of Government demonstrated their commitment to combat NCDs through the Port-of-Spain Declaration, which strongly encouraged the establishment of National Commissions

on NCDs to plan and coordinate the prevention and control of NCDs, surveillance systems, and research programs in collaboration with universities [3].

Barbados is a high-income island nation in the Caribbean, with an area of 432 square kilometers (166 square miles) [4] and a population of 277,821 (in 2010), of which 92% are black [5]. In response to the Port-of-Spain declaration, the Ministry of Health established the National NCD Commission and contracted the University of the West Indies (UWI) to manage a population-based, multi-NCD surveillance system on its behalf, and with oversight from the Commission: the Barbados National Registry for Chronic NCD (the BNR). The BNR was launched in 2007 through initial funding from the European Development Fund; it comprises three registries: BNR-Cancer, BNR-Stroke, and BNR-Heart. The registries collect data on new cases of cancer, stroke, and acute myocardial infarction, respectively, and produce statistics concerning incidence, mortality, and survival. The BNR registries were

* Corresponding author at: Centers for Disease Control and Prevention, DCPC, 4770 Buford Highway, NE, Mailstop K-76, Atlanta, GA, 30341-3717, USA.
E-mail address: fbt9@cdc.gov (T.N. Martelly).

implemented in stages to allow adequate time for planning each type of data collection. The start-up phase required substantial investment in hiring and training personnel, and time to ensure that appropriate support infrastructure was available to initiate data collection, perform quality review, and implement initial registry findings to further improve the registration procedures. The phased introduction began in July 2008 with BNR-Stroke, followed by BNR-Heart in July 2009 and BNR-Cancer in July 2010. Barbados does not have a coordinated electronic health information system, and case reports require abstracts from mostly paper-based patient records.

Population-based NCD registries are important for measuring trends, epidemiological research, public health planning, evaluation of prevention and control programs, and patient care improvement processes [6]. Although the importance of population-based NCD registries to a country is readily justifiable, such registries involve cost and may not be sustainable during times of economic constraint. The aim of this study is to identify differences in the resources used to operate a cancer registry and CVD registry in Barbados, and to suggest areas that could improve registry efficiency. For policy-makers who make decisions about budgets for public health activities, economic evaluation of registries helps to document the resources required to sustain registration activities. Additionally, cost assessment can be used to improve cost effectiveness and efficiency-of-registry operations [7,8]. In addition, details on the cost of the BNR approach for collecting data on cancer and cardiovascular diseases (CVDs) such as stroke and acute myocardial infarction (heart attack) may help inform other countries developing plans to establish NCD registries.

2. Methods

2.1. Registry data collection approach

The data collection mandates, methods, and operational processes for the BNR, as well as the details on the data elements collected, have been described previously [9]. The BNR registration activities are designed to meet specific objectives identified as key areas of importance in NCD surveillance in Barbados. The BNR reporting obligations are listed below.

- 1) Total number of case registrations expressed as a proportion of the population (%).
- 2) Total number of hospital admissions for cancer or CVD events expressed as a proportion of the number of registrations (%).
- 3) Total number of cancer or CVD events expressed as a proportion of the number of case registrations (%).
- 4) Average length of hospital stay (in days) for cancer or CVD events.

The BNR-Stroke and BNR-Heart currently use a mixture of active and passive case-finding, and follow similar data-collection approaches. After cases are verified as eligible for registration, BNR staff abstract the patient notes and then enter that information into the registry database. One set of data abstractors collects the required data elements for both stroke and heart-attack events. These data elements include treatment, date of last contact, and status of last contact at patient follow-up (28 days and 1 year post-event). BNR-Cancer follows different requirements and has a separate dedicated team of data abstractors. To facilitate the analysis presented in this study, we report data for BNR-Cancer and a consolidated CVD component (BNR-CVD) with combined information for the stroke and heart-attack registries.

Table 1 shows the differences between the CVD and cancer-registry data collection procedures. The CVD component (BNR-Heart and BNR-Stroke) identifies incident cases prospectively on a continuing annual basis, and follows the World Health Organization STEPwise approach to stroke surveillance (WHO STEPS), which involves collecting data from hospitals, the national death registration system, and the community [10]. The cancer component (BNR-Cancer) identifies incident cases collected retrospectively (for one specific year), generally from hospitals, laboratories, and the national death registration system. BNR-Cancer follows the processes created by the International Agency for Research on Cancer (IARC) [11] and collects the recommended minimum data elements, such as treatment, date of last contact, and status at last contact, using the established definitions. For the first year of data collection, the cancer registry collected data on all types of skin cancers, including non-melanoma; however, for the second year, the registry collected data only on melanomas. The second year of data is still under internal review processes and has not yet been through internal or external validation for quality and completeness.

As further described in Table 1, the BNR-CVD and BNR-Cancer registries differ not only in their data collection approach but also in all the processes used to capture the data elements. The number of data elements collected for each stroke and heart attack case is about four times higher than the number for cancer cases; however, for cancer cases, more sources are visited, and many more suspected-patient notes are reviewed to register a case. Two abstractors are assigned to cancer, compared with four for the CVD registries, and cancer cases do not require active follow-up data collection, as is done for the CVD registry components.

Despite these differences, several key activities are shared across the registries. These include administration, management, data analysis and tabulation, database management, quality assurance, and community outreach and training. All registry staff share a common space, infrastructure, and communication tools.

Table 1

Differences between the cancer- and cardiovascular-disease-registry components of the Barbados National Registry, April 1, 2014–March 31, 2015.

	Cancer registry	Cardiovascular disease registries
Data collection approach	Retrospective	Prospective
Data capture process	Direct data entry using laptops	Paper case-reporting form; scanned into database
Number of data elements collected ^a	187	1563 (stroke: 729, heart: 834)
Average number of data sources visited to register one case	5	2
Average number of suspected-patient notes investigated to register one confirmed case	15	5 (heart); 1.5 (stroke)
Number of data abstractors	2	4
Patient follow-up	Passive follow up with Death-record linkage	Active case follow up

^a The data elements collected include the treatment variable.

2.2. Cost data collection approach

We used the modified Centers for Disease Control and Prevention’s (CDC’s) International Registry Costing Tool (*IntReg-Costing Tool*) to collect cost data from the BNR-CVD and BNR-Cancer registry components [12]. The tool was originally designed to collect cost data from cancer registries, and was modified to collect data from the Barbados NCD registry with integrated cancer and CVD registry activities. In each of the ten modules of the *IntRegCosting Tool* we provide separate categories to report cost and resource-use data specific to each registry component. When there were shared expenditures across registries, we provided an option for reporting the proportion of the cost that was allocated to each. For example, when labor was shared, the time spent on each registry activity by component was used to assign the proportion of cost. For rental cost of shared space, the proportional cost was based on the number of square feet used.

We collected the cost data from the perspective of the registry, and therefore collected data on all resources required to support registry operations. These sources included financial support as well as non-monetary contributions from the host institution, the Chronic Disease Research Centre (CDRC) of the UWI. We used financial records from the BNR and CDRC to determine the registry’s incomes and expenditures from April 2014 to March 2015. We asked registry and CDRC personnel to account for their registry-specific activities within and across registries (where applicable) using percentages. All registry staff were able to allocate their time to the standardized set of registry activities provided in the *IntRegCosting Tool*. The User’s Guide provided with the tool offered guidance on completing the tool along with definitions for the standard set of activities.

3. Calculations

On the basis of the allocation provided in the *IntRegCosting Tool*, we assigned cost by budget categories to BNR-CVD and BNR-Cancer. We categorized cost into registry staff, consultants, materials and travel, and administrative or indirect costs. Additionally, we assigned resources to each activity performed

by the registry; labor costs were allocated on the basis of the proportion of time spent on each activity and registry (cancer or CVD). To accurately estimate cost of labor, salary information was available for each registry staff member. Similarly, we assigned the non-labor resources component to each activity and registry, and we used “best-case” estimates to determine the value of non-monetary contributions using previously tested economic methods [13–15].

At the time of the initiation of BNR-Cancer (2010), at least 2 years post-diagnosis was needed to allow for complete data to be available, including treatment information. Therefore, the first year of data collected was for patients diagnosed in 2008. The 2008 cancer-case data were collected over a 3-year period (2011 through 2014), which represents the start-up phase of the cancer registry. We believe that in the future, as the registry becomes more established, it will take less time to collect a single year of incidence data, because the initial requirements – intensive staff training and time required to work out details on specific data collection procedures – will not be needed. If additional data, such as stage at diagnosis, are collected in the future, then staffing needs will change. We present both an established phase estimate and start-up phase estimates for the cancer cases, which reflect collection of a single year of incident cases over a 2-year versus a 3-year period. The cases reported for BNR-CVD and BNR-Cancer are used as the denominator value in calculating the cost per case, that is, the estimated cost to the registry to report one incident case. We report the total cost per case as well as the cost per registry activity to allow us to systematically compare the BNR-Cancer and BNR-CVD operations. For conversion from Barbadian dollars (BD\$) to US dollars (US\$), we used 1 US\$ = 2 BD\$.

4. Results

The total expenditure for the BNR for the annual period from April 1, 2014 to March 31, 2015 was BD\$1,128,907 (US\$564,453). Financial resources from the Ministry of Health comprised 56% of the resources, for a total of BD\$634,321 (US\$317,161), and the remaining resources comprised contributions from the host institution, UWI’s CDRC (data not shown). Fig. 1 illustrates the

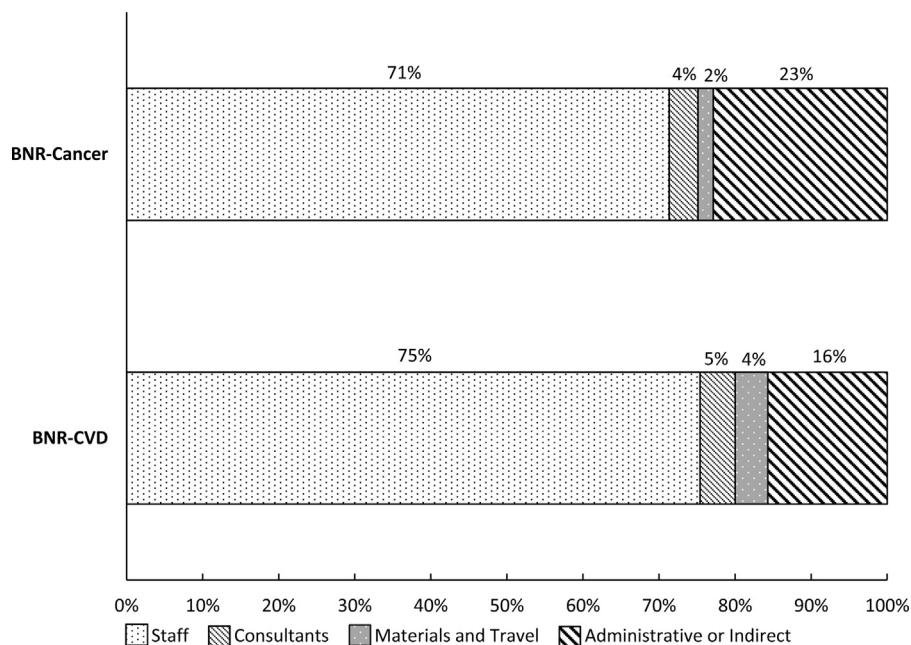


Fig. 1. Barbados Registries’ resources by budget categories, April 1, 2014–March 31, 2015. BNR, the Barbados National Registry for Chronic Non-communicable Disease; CVD, cardiovascular disease.

distribution-by-budget category for BNR-Cancer and BNR-CVD. Both registries had a similar distribution, with registry labor incurring the highest proportion of the cost at 71% and 75% for BNR-Cancer and BNR-CVD, respectively. BNR-Cancer used 23% of resources for administrative or indirect costs, and BNR-CVD used 16%; other costs related to consultants, materials, and travel made up less than 10% of the total cost for both registry components.

Fig. 2 shows the 13 registry activities and administration-related costs reported during this period for both registry components. For cancer, we report both an established phase and a start-up phase cost-per-case estimate, which reflects collection of 1 year of incidence data over a 2-year or 3-year period, respectively. Overall, the top four highest-cost activities for both BNR registry components were management, administration, data collection, and data analysis and tabulation. For the fixed-cost activities – for example, cost of management and administration – that will not vary with the volume of cases registered over the short term, the BNR-CVD and the low-cost BNR-Cancer were generally quite similar. The 3-year BNR-Cancer estimates were higher. Among the variable cost activities that depend on the volume of cases: (1) BNR-CVD incurred higher costs than BNR-Cancer for data collection and database management; (2) BNR-CVD incurred costs between the start-up phase cost and established phase cost for BNR-Cancer for data analysis and tabulation; and (3) BNR-CVD had a lower cost than BNR-Cancer for quality assurance.

Table 2 presents the total cost per case for each of the BNR registry components. The cost per case for BNR-Cancer was BD \$764 (US\$382) when data collection was done over a 2-year period and BD\$1146 (US\$573) when data collection required a 3-year period. The cost for collecting and reporting one case was BD\$978 (US\$489) for the BNR-CVD registry.

5. Discussion

This paper provides the results and lessons learned from the economic evaluation carried out on the BNR operations using the

IntRegCosting Tool. A substantial proportion of the registry operations expenditure is related to staff employed by the registry, reflecting the labor-intensive nature of collecting and reporting incidence cases worldwide, Europe included [12,16,17]. The cost per cancer case for the BNR-Cancer registry (US\$382–US\$573) is six to nine times higher than the cost per cancer case collected by the registries funded by the CDC; the average cost per case for the US registries is about US\$61 [7,8], with low-volume registries incurring a higher cost per case than high-volume registries. The cost per cancer case for the BNR-Cancer registry is higher than the average cost per cancer case collected by European registries, which is about US\$70 [17]. The cost is also significantly higher than the cost-per-case registries in low- and middle-income countries (LMICs) studied by Tangka et al., which ranged from US\$4 (Mumbai, India) to US\$113 (Pasto, Colombia) [16]. There are several potential reasons for the BNR-Cancer's costs being comparatively higher than those of US and LMIC registries. The Barbados registries are in the early stage of operation, with some start-up-related activities still ongoing (for example, optimization of the data collection approach), collection of a small volume of cases (larger volumes result in economies of scale), and the facing of additional challenges in data collection, including the need to abstract much of the data from paper records.

The data from the BNR has not yet undergone quality and completeness checks to be included in *Cancer Incidence in Five Continents*. Although cancer is a reportable disease, passive notification from private physicians remains low; after BNR staff visits to physicians, however, there was some improvement. Currently, the team uses active surveillance by performing regular call-rounds to all private physicians known to diagnose cancer patients, as well as by collecting information from laboratories and the national death register. Additionally, BNR team members are working with the Ministry of Health to revise pathology regulations to allow notification of all suspected and confirmed cancer cases directly to BNR by laboratories island-wide [9].

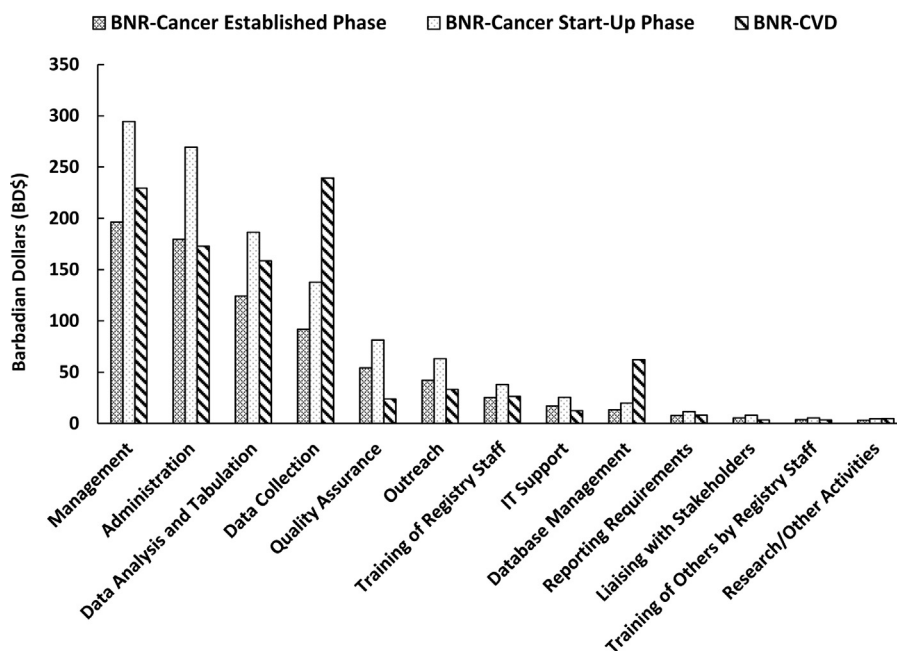


Fig. 2. Barbados Registries' cost per case by activity, April 1, 2014–March 31, 2015. Cancer cases were collected retrospectively over multiple years, and therefore we present an established-phase estimate and a start-up-phase estimate for cost per case assuming a 2- or 3-year period for data collection. The established phase cost-per-case estimate corresponds to the 2-year period of data collection, and the start-up-phase cost-per-case estimate is for the 3-year period. For cardiovascular disease (CVD), we report an annual estimate using the average monthly cases based on 2013 and 2014 incident cases. 1 United States dollar (US\$) = 2 Barbadian dollars (BD\$). BNR, the Barbados National Registry for Chronic Non-communicable Disease.

Table 2
Barbados Registry cases and cost per case.

	Cancer (BNR-cancer)	Cardiovascular (BNR-CVD)	
	Established phase (cases collected over 2 years)	Start-up phase (cases collected over 3 years)	Average
Incident cases collected (per year) ^a	602 cases	401 cases	684 cases
Cost per case ^{b,c}	BD\$764	BD\$1146	BD\$978

BNR, the Barbados National Registry for Chronic Non-communicable Disease; CVD, cardiovascular disease.

^a There were 1204 total cancer incidence cases during 2008. Cancer cases were collected retrospectively over multiple years, and therefore we present an established phase estimate and a start-up phase estimate for cost per case assuming a 2- or 3-year period for data collection. The established phase cost-per-case estimate corresponds to the 2-year period of data collection, and the start-up phase cost-per-case estimate is for the 3-year period. For CVD, we report an annual estimate using the average monthly cases based on 2013 and 2014 incident cases.

^b Cost per case is defined as the total costs by cancer or CVD registry for the reporting period divided by the incident cases collected during the reporting period.

^c 1 United States dollar (US\$) = 2 Barbadian dollars (BD\$).

The BNR-Cancer performs only retrospective data collection (no change in the data-collection approach is currently planned), whereas the BNR-CVD collects data prospectively for a much larger set of data elements on a daily basis, and is also engaged in active post-event follow-up of patients. Given these differences, we would expect that the BNR-Cancer cost per case would be substantially lower than that of BNR-CVD. There are several potential explanations as to why we did not find substantially lower costs for BNR-Cancer estimates. First, we report the total cost, which includes both the fixed and the variable costs. When we separate these costs, we find that the variable components of CVD, such as data collection and database management, are higher than those for cancer. Second, much of the cost for both the CVD and cancer registries is cost associated with management and administration. For the cancer registry, which was initiated after the CVD registry, we assume that many fixed costs related to these activities were already present. Therefore, the addition of the cancer registry (incremental cost) increased only the variable components, including the need to assign additional data abstractors. In this instance, the addition of the cancer registry to an already existing infrastructure did not result in a much lower cost per case.

Although there are potential efficiencies related to collecting data on diagnosis, treatment, and outcomes retrospectively for a specific year of cancer diagnosis (over a 2-year or 3-year period), economies of scale can also occur with simultaneous collection of multiple years of cancer incidence data. This is because, during data collection for only a specific year, abstractors ignore data that they come across for cancers not diagnosed during the year of interest. In contrast, for multiple years, during any data-collection visit abstractors collect all cancer cases regardless of the year of diagnosis; for the latter, it is the reporting, not the abstraction, that is driven by year of diagnosis. With retrospective data collection, at least in some instances, patient records may not be as easily accessible as prospective data collection, because medical charts for patients who have completed treatment may have been archived. BNR-Cancer has chosen to focus on a 2-year or 3-year retrospective period because of the lack of resources to hire adequate staff and provide other non-labor resources to collect cancer-case incidence on a continuous basis. To facilitate future planning, a comparative study could be performed on the resources needed for abstraction of a single year of cancer cases diagnosed versus multiple years of cancer cases diagnosed, abstracted on a continuous basis.

Although there is no coordinated electronic health information system in Barbados, the BNR is making efforts to improve efficiency in data collection. The BNR-Cancer process involves data input from patient records directly into an electronic database, and the BNR-CVD is moving toward more electronic data capture, with the aim of eliminating paper-based data collection. The lessons learned thus far include the need to allow for a significant amount

of time for staff training and implementation because of the steep learning curve involved in converting from paper to an all-electronic format. In addition, the ability to navigate between data elements or sections may be more cumbersome with electronic data sheets than with paper forms. In the future, the BNR surveillance cost may be lower with the introduction of the proposed electronic health information systems throughout the island. Such a system could allow for enhanced direct electronic data capture from the hospital medical department records and databases, but there could also be unanticipated issues related to data quality that will need to be carefully reviewed before full-scale use by the registry.

The BNR operations are complex, entailing multiple registries with differences in data-collection approaches. In this study we have attempted to use standardized definitions to enable comparison between BNR-Cancer and BNR-CVD registry cost components. A potential limitation stems from the differences in procedures that may lead to variation in how resources – such as staff time – are allocated to registry activities. Additionally, we collected only 1 year of cost data from the BNR, which is usually funded in 3-year cycles. There may be year-to-year variations that were not captured using the single year of data reported in this study. Finally, the BNR is still in the early phase of data collection, especially in terms of cancer cases, and therefore data-collection procedures and other registration processes may evolve over time as lessons learned are incorporated to further improve the efficiency of registry operations.

The data from the BNR have been used to inform national guidelines on death-certification data quality, as well as to provide the evidence for the opening of a cardiac suite and acute stroke unit at the only national public hospital on the island. BNR data will be used to evaluate the outcomes of these two critical care wards in the near future. Additionally, BNR has been instrumental in improving patient care through its biannual training seminars targeting medical doctors and nurses.

The BNR is a unique, multi-NCD registry that collects information on cancer, stroke, and heart attack. Although their data collection approaches differ, the BNR-CVD and BNR-Cancer registries share management resources and other fixed costs such as office space. Intuitively, this could have resulted in efficiencies, but we were unable to systematically assess the potential cost effectiveness of integrating multiple registry operations within a single entity. Future studies need to be designed to quantify potential efficiencies, as the findings will be very valuable for other small-island nations that are in the process of planning the structures of their NCD surveillance operations.

6. Conclusions

This study illustrates how economic evaluation can provide evidence for making decisions about funding and operational

efficiency to ensure that the BNR can operate sustainably and continue to make important contributions to improving the quality of care in Barbados. The registry, especially BNR-Cancer, is still in the early stages of implementation. The findings from this study and lessons learned from ongoing data-collection efforts will allow BNR-Cancer to optimize operations.

Conflicts of interest

none

Disclaimer

The findings and conclusions in this paper are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

Author contributions

Tanya Martelly: Lead author; manuscript conception and design; interpretation of data; drafted the manuscript; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Angela Rose: Co-author; interpretation of data; 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; table/figure creation; revised manuscript for intellectual and scientific content; reviewed and approved final version to be published.

Florence Tangka: 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.

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

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