



# Establishing national noncommunicable disease surveillance in a developing country: a model for small island nations

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## Suggested citation

Rose AM, Hambleton IR, Jeyaseelan SM, Howitt C, Harewood R, Campbell J, et al. Establishing national noncommunicable disease surveillance in a developing country: a model for small island nations. *Rev Panam Salud Publica*. 2016;39(2):76–85.

## ABSTRACT

**Objective.** To describe the surveillance model used to develop the first national, population-based, multiple noncommunicable disease (NCD) registry in the Caribbean (one of the first of its kind worldwide); registry implementation; lessons learned; and incidence and mortality rates from the first years of operation.

**Methods.** Driven by limited national resources, this initiative of the Barbados Ministry of Health (MoH), in collaboration with The University of the West Indies, was designed to collect prospective data on incident stroke and acute myocardial infarction (MI) (heart attack) cases from all health care facilities in this small island developing state (SIDS) in the Eastern Caribbean. Emphasis is on tertiary and emergency health care data sources. Incident cancer cases are obtained retrospectively, primarily from laboratories. Deaths are collected from the national death register.

**Results.** Phased introduction of the Barbados National Registry for Chronic NCDs (“the BNR”) began with the stroke component (“BNR–Stroke,” 2008), followed by the acute MI component (“BNR–Heart,” 2009) and the cancer component (“BNR–Cancer,” 2010). Expected case numbers projected from prior studies estimated an average of 378 first-ever stroke, 900 stroke, and 372 acute MI patients annually, and registry data showed an annual average of about 238, 593, and 349 patients respectively. There were 1 204 tumors registered in 2008, versus the expected 1 395. Registry data were used to identify public health training themes. Success required building support from local health care professionals and creating island-wide registry awareness. With spending of approximately US\$ 148 per event for 2 200 events per year, the program costs the MoH about US\$ 1 per capita annually.

**Conclusions.** Given the limited absolute health resources available to SIDS, combined surveillance should be considered for building a national NCD evidence base. With prevalence expected to increase further worldwide, Barbados’ experiences are offered as a “road map” for other limited-resource countries considering national NCD surveillance.

## Key words

Health surveillance; cardiovascular diseases; neoplasms; West Indies; Barbados.

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World Health Organization (WHO) projections in 2006 indicated that by 2030, almost three-quarters of deaths globally would be caused by chronic noncommunicable diseases (NCDs) (1). The Global Burden of Disease Study showed that, in 2010, two of the five leading causes of global morbidity were NCDs (ischemic heart disease and stroke), which had increased in importance in the 20 years since 1990 (2). WHO's World Health Statistics 2013 reported global mortality rates from NCDs in 2008 that were almost twice the rate for injuries and communicable diseases combined (3), and this NCD preponderance was repeated in the Americas region in 2013 (4).

In 2012, WHO produced the NCD Monitoring Framework, outlining a set of nine targets for member states to achieve by 2025, with 25 accompanying indicators (5). These indicators allow for the reporting of country-level progress toward targets, and include as major elements the prospective monitoring of NCD morbidity and mortality (6).

In 2007, Caribbean governments committed to combatting the NCD burden in the region, in the Port-of-Spain Declaration (7). In Barbados, the Ministry of Health (MoH) and The University of the West Indies (UWI) jointly initiated the Barbados National Registry for Chronic

NCDs ("the BNR"): a population-based, multi-NCD registry designed for resource-limited settings. This report describes the surveillance model used to develop the registry (one of the first of its kind worldwide); registry implementation; lessons learned; and incidence and mortality rates from the first years of operation.

## MATERIALS AND METHODS

A unique, national, population-based surveillance system was developed and implemented for effective and efficient monitoring of the three major NCDs in Barbados, a small island developing state (SIDS) in the Eastern Caribbean. Model design criteria included simplicity and economy of scale. Core or "minimum" datasets for cancer, acute myocardial infarction (MI) (heart attack), and stroke were based on international guidelines (8, 9) and model registries implemented elsewhere (10, 11). Local stakeholders were given the opportunity to propose locally relevant data items.

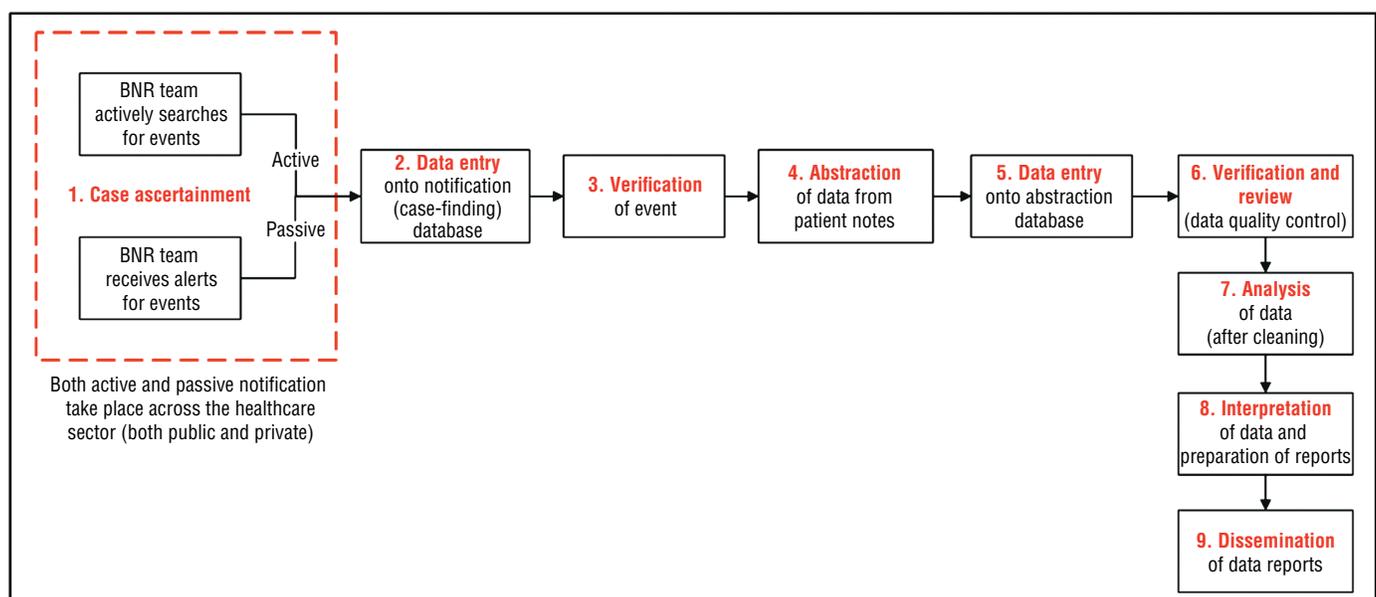
The BNR is divided into three components: BNR–Stroke, BNR–Heart, and BNR–Cancer. Combining three NCD registry components into one helps to maximize efficiency and minimize cost by allowing sharing of both staff (statistical, analytical, and administrative support,

as well as overall leadership and management of the BNR) and office space. Costs are also kept low by engaging volunteer staff to assist with administrative duties and encouraging public health graduate and medical students to participate in unpaid internships to assist with surveillance and data analysis.

Details about the methodological processes for the BNR are provided in [Supplementary material: 1 and 2](#), which describes the operational processes for all three registry components and includes the case definitions used by the BNR and an outline of the variables collected. Ethical approval for the BNR was obtained from both the national institutional review board and the local hospital ethics committee, and these approvals are renewed annually.

The data collection processes for each of the three registry components are outlined in Figure 1 and described in detail in [Supplementary material 1](#). The cardiovascular disease (CVD) components (BNR–Heart and BNR–Stroke) identify incident cases prospectively, and follow the WHO STEPwise approach to stroke surveillance, which recommends collecting data from three primary sources (hospital, national death register, and community) (9) (Table 1). The cancer component (BNR–Cancer) identifies incident cases retrospectively, primarily

**FIGURE 1. Operational process for the national multi-disease registry, Barbados, 2015**



**Source:** compiled by the authors based on the study processes.

from hospital laboratories and the national death register, and was designed to follow processes created by the International Agency for Research on Cancer (IARC) (8), including the recommended minimum dataset. Retrospective cancer case ascertainment allows diagnosis, treatment, and outcome data to be abstracted at one time, thus minimizing the workload. At the time of data collection (2010), there was a two-year delay in data abstraction, so the first year of data collected was for patients diagnosed in 2008. Details about data items collected during data abstraction are shown in [Supplementary material 2](#).

All cases of all three NCDs monitored (acute MI, cancer, and stroke) for all ages nationwide are registered (i.e., cases are not limited to “first-ever” events), as long as they are Barbados residents. For all three registry components, residency is defined, following the Barbados census, as those who have lived on the island for at least six of the previous 12 months (12).

Statistical analyses are conducted for the current year’s quarterly and annual stakeholder reports. Primary endpoints are incidence, mortality, case fatality, and survival. Incidence and mortality per 100 000 population are calculated with 95% confidence intervals (CIs) based on the gamma distribution, as described by Fay & Feuer (1997) (13). For the two CVD components, case fatality analyses reflect proportions of deaths 28 days and one year from the causative event. For cancer, survival is estimated at five years post-diagnosis. All analyses are conducted using Stata 12 (StataCorp, College Station, Texas, United States).

During the preparation phase of registry implementation, the number of each type of event to be registered was estimated in order to estimate the registry workload, for human resource planning. Data from a prior study that measured all first-ever strokes (FES) between 2001 and 2004 (14) were used for the baseline estimate of the number of registrants for the BNR–Stroke. For BNR–Heart, data on acute MI patients discharged alive from 2000 to 2008 from the Queen Elizabeth Hospital (QEH), Barbados’ premier public health care institution, were combined with data on national deaths from acute MI or sudden cardiac death reported to the WHO Mortality Database (15) for the same period (16). Cancer numbers were

estimated based on incidence data from an earlier study of breast and prostate cancers in Barbados (17) and incidence data for the African-American population in the United States from National Institutes of Health (NIH) National Cancer Institute Surveillance Epidemiology and End Results (SEER) program reports (18).

Phased introduction of the three registry components began in July 2008, with the BNR–Stroke, followed by the acute MI component, BNR–Heart (July 2009), and the cancer component, BNR–Cancer (July 2010). Implementing the system in three stages allowed for more flexibility for human resources, with the necessary system adjustments and training carried out as each part of the system was added. For example, members of the data collection team trained to implement the two CVD registry components had at least one year of experience in acute event data collection by the time the BNR–Cancer began. This enabled the identification of the team members best suited for training in cancer registration, which is more demanding than that for CVD registration, and also necessitates international travel.

## RESULTS

### Outcomes from planning studies

Based on data from the previous national stroke register (14, 19), approximately 378 confirmed annual FES events (Table 2) and approximately 900 confirmed annual stroke events of all types (data not shown) were expected. The pre-registry feasibility study investigating the QEH discharge records (2000–2008) estimated a mean of 219 acute MI patients per year during the period (16). In the same study, predictions of future numbers, accounting for population ageing, included a mean estimate of 372 acute MI patients per year during 2009–2013 (Table 2). The estimated number of cases for the cancer component based on the SEER data (18) (1 395) is shown in Table 2.

### Case ascertainment

As a guide to the capacity of the data collection team to locate and abstract full information on hospitalized CVD patients, there were 2 183 full abstractions from 2 494 hospital admissions (88%) for

**TABLE 1. Data sources for the cardiovascular disease (Heart<sup>a</sup> and Stroke) and Cancer components of the national registry (BNR), Barbados, 2009–2013**

Data source	BNR–Heart and BNR–Stroke	BNR–Cancer
Primary		
Public sector		
Queen Elizabeth Hospital	Accident and emergency department Medical records department Death records department Wards	Laboratory Death records department
Death register	National	National
Private sector		
Health facilities	Emergency (4)	BayView Hospital
Physicians	– <sup>b</sup>	> 300
Secondary		
Public sector		
Queen Elizabeth Hospital	Radiology department Rehabilitation department	Radiotherapy department Medical records department Death records department Radiology department
Polyclinics	8 (plus 4 district and geriatric hospitals)	8 (plus 4 district and geriatric hospitals)
Private sector		
Health facilities	BayView Hospital Rehabilitation	Laboratories <sup>c</sup> Emergency (4)
Physicians <sup>d</sup>	> 300	–

**Source:** compiled by the authors based on surveillance data.

<sup>a</sup> Acute myocardial infarction (MI).

<sup>b</sup> Not applicable.

<sup>c</sup> Selected, for some data (although all private laboratories are potential data sources for the BNR–Cancer, cancer is not yet notifiable by law from laboratories to the Ministry of Health in Barbados, so data provision from private laboratories to the BNR–Cancer is not routine).

<sup>d</sup> Including cardiologists and neurologists (although all private physicians are potential data sources, not all have agreed to provide information to the BNR).

**TABLE 2. Expected (based on prior or external research) versus actual disease burden for all components of the national registry (BNR), Barbados, 2009–2013**

Indicator	(BNR–Stroke)		(BNR–Heart <sup>a</sup> )		(BNR–Cancer)	
	Expected <sup>b</sup> (2001–2004)	Actual <sup>c</sup> (2009–2013)	Expected <sup>d</sup> (2009–2013)	Actual (2009–2013)	Expected <sup>e</sup> (2008)	Actual (2008)
Case ascertainment ratio <sup>f</sup>	— <sup>g</sup>	1.5 : 1	—	5 : 1	—	15 : 1
Annual incidence per 100 000 (95% confidence interval)	140 (126–155)	54–117 <sup>h</sup> (45–131)	128 (106–151)	126 (113–140)	502 (495–510)	433 (409–459)
Number of new events per year (month)	378 (32)	149–326 (12–27) <sup>h</sup>	372 (31)	349 (29)	1 395 (116)	1 204 (100)
In-hospital case fatality rate (CFR) (%)	N/A <sup>i</sup>	28–29 <sup>h</sup>	27	40	—	—
28-day CFR for hospitalized patients (%)	30	35 <sup>h</sup>	N/A	45	—	—
28-day CFR for all patients (including those who died before reaching hospital) (%)	N/A	54 <sup>i</sup>	N/A	70	—	—
Full abstractions/hospital admissions (%)	N/A	2 183 / 2 494 (88) <sup>j</sup>	N/A	635 / 857 (74)	N/A	N/A

**Source:** compiled by the authors based on study results and external data sources (cited below).

<sup>a</sup> Acute myocardial infarction (MI).

<sup>b</sup> Crude incidence rates based on data for first-ever stroke (FES) only from the Barbados Register of Strokes (2001–2004) (earlier stroke registry in Barbados) (14).

<sup>c</sup> Crude incidence rates based on data for FES from the BNR.

<sup>d</sup> Crude incidence rates based on data for events and deaths from hospital records and internationally reported cause of death data, 2000–2008 (16).

<sup>e</sup> Data collection began in 2010 and is complete for first year of data collection (2008). Expected events based on SEER U.S. (African-American) incidence for 2008; incidence rate age-standardized to U.S. 2000 standard population (<http://seer.cancer.gov/stdpopulations/stdpop.19ages.html>) to enable comparison.

<sup>f</sup> Number of patients whose records need to be examined to determine eligibility for a single confirmed registration (e.g., for stroke, after examining three suspected patients' records, two will be registered as confirmed strokes, on average, whereas about five suspected patients' records will need to be examined to register one confirmed acute MI).

<sup>g</sup> Missing data.

<sup>h</sup> Ranges reflect the high proportion (almost one-third) of hospitalized stroke patients without prior stroke documentation (the lower end of the range assumes no patients without prior stroke documentation were FES patients, while the higher end of the range assumes all patients without prior stroke documentation were FES patients). Where there is a single proportion (no range), the proportions with and without prior stroke documentation were the same.

<sup>i</sup> All strokes (i.e., not just first-ever events).

<sup>j</sup> Not applicable.

all strokes in 2009–2013 and 635/857 (74%) for acute MI in 2009–2013 (Table 2). The unabstracted hospital admission case information corresponded to deceased patients for whom the data collection team experienced difficulty obtaining hospital records.

The hospital case ascertainment rate is defined as the ratio of confirmed registered events to all events followed through the hospital prior to confirmation. For the BNR–Stroke, the rate was about 3:2 (Table 2). For the BNR–Heart, the rate was approximately 5:1. For the BNR–Cancer, there was a case ascertainment ratio of almost 15:1, illustrating the extent of the case ascertainment workload for that component. Unlike the two CVD components, in the BNR–Cancer, records can be deemed ineligible at each stage of record review, as other data sources that may show an earlier date for the patient's visit can be identified during each step of the process. If the case ascertainment process identifies an earlier potential incidence date (defined as the date of the first physician visit during which cancer was suspected), the cancer event would be ineligible for registration in the current year.

## Data

A flowchart depicting the number of suspected CVD cases in one year of complete registry data (2011), with the confirmed number of registrations (295 for acute MI and 569 for all strokes) and hospitalized patients (159 and 470 respectively), is shown in Figure 2a. A similar chart is shown for the BNR–Cancer in Figure 2b.

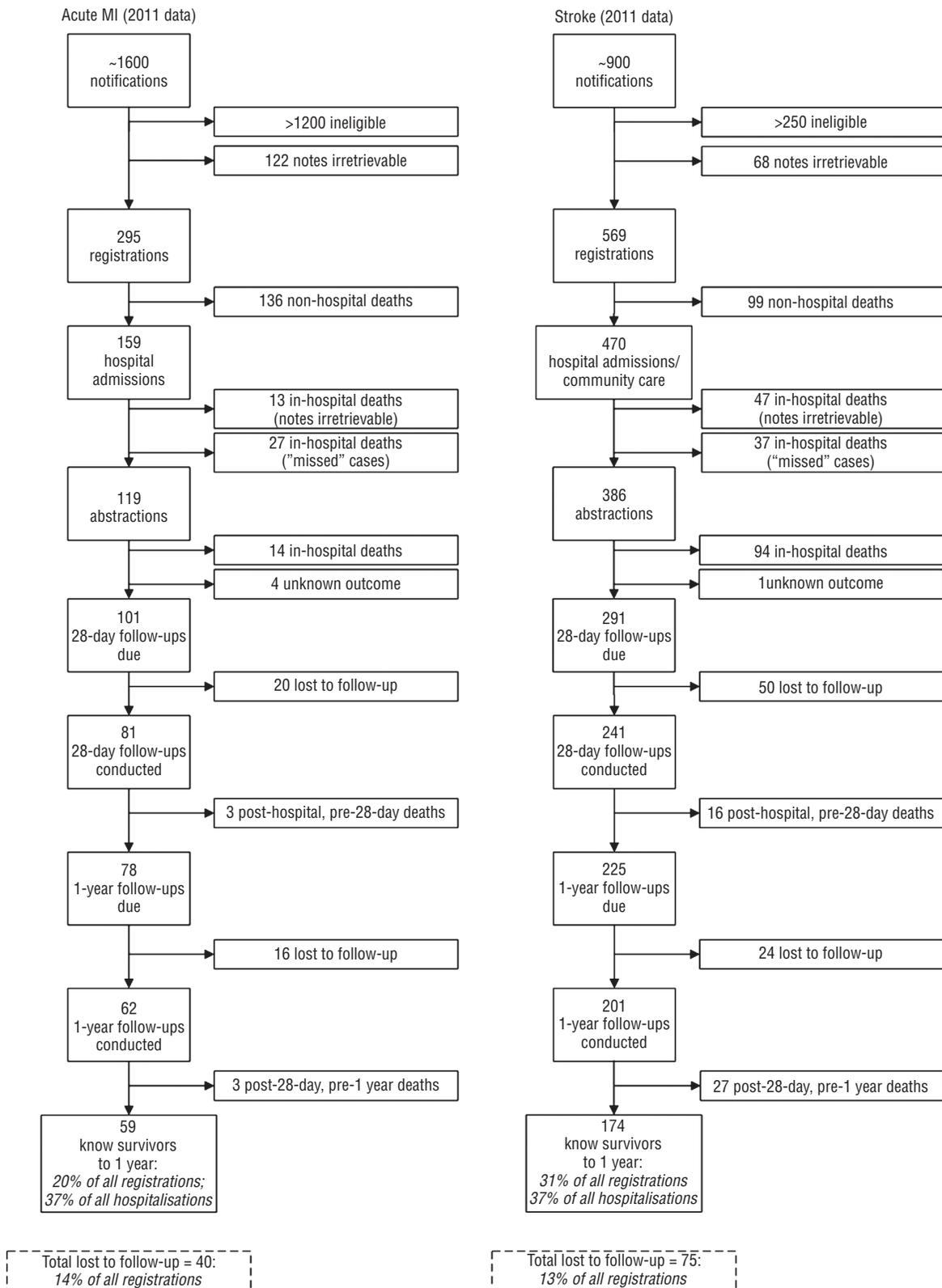
Data collected for the first five complete years (January 2009–December 2013) for all stroke events show a mean of 593 events per year (data not shown). Follow-up data show that on average 31% of all stroke registrations survive to one year (Figure 2a). The annual mean number of acute MI patients during the first five complete years of that registry component's operation (2009–2013) was 349 (Table 2), and follow-up data show that on average 20% of all acute MI registrations survive to one year (Figure 2a). For 2008, the team abstracted data for 1 117 confirmed cancer patients (1 204 events), of whom 61% were still alive by the date of abstraction (two years or more from diagnosis) and 39% had died five years from diagnosis (Figure 2b).

## Cost

During the initial start-up phase (the first four months), 75% of the budget for the multi-disease BNR was allocated to salary costs and 25% to non-salary costs. Non-salary costs during this period included expenses for 1) computer hardware and software (desktop computers for eight staff members, a printer, a scanner, and the license for the optical character recognition software, Cardiff TeleForm® (version 10.4, HP Autonomy, San Francisco, California, United States)); 2) office desks and tables; 3) site visits to other countries with existing registries; and 4) recruitment and training of the initial staff for the first registry component (BNR–Stroke).

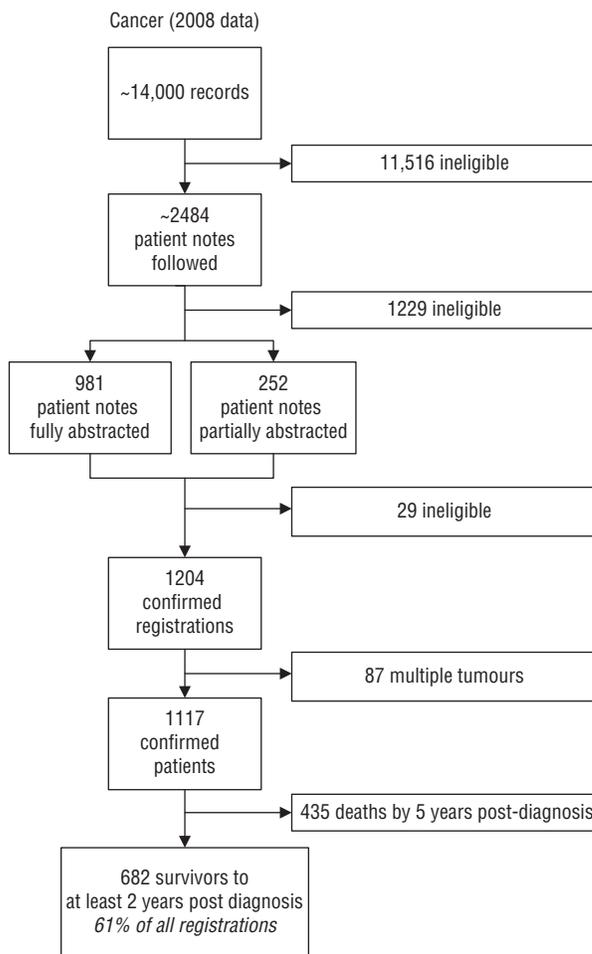
In later years, the proportion of budget used for salary costs shifted to and remains at almost 95% (including costs for registry data collection and administrative and management staff) (Figure 3). This change was largely due to the realization over time that more data abstraction staff were required than initially planned, due to the continued very active nature of data collection from the main data source (the QEH). Currently,

**FIGURE 2a. National registry data flowcharts for acute myocardial infarction patients (“BNR–Heart”) and stroke patients (“BNR–Stroke”), showing numbers at each stage of data collection, from notification to one-year follow-up, Barbados, 2011**



Source: compiled by the authors based on the study results.

**FIGURE 2b. National registry data flowchart for cancer patients (“BNR–Cancer”), showing numbers at each stage of data collection, from notification to two years post-diagnosis, Barbados, 2008**



**Source:** compiled by the authors based on the study results.

and a single public hospital (the QEH) operating as the island’s major tertiary referral center. The private system, where services are provided for a fee, comprises one small hospital for elective procedures, six emergency service facilities, and numerous specialists and general practitioners (GPs), as well as private diagnostic services. A recent study of human resources in health care estimated that, in 2009, of 420 medical doctors registered in Barbados, 55 practice only privately, 168 are employed only by the public health care service, and 197 practice in both public and private health care sectors (20). Members of the public obtain health care services from the public sector, the private sector, or (most commonly) a combination of both. There is no centralized system for collecting and managing patient information, and patients may visit different GPs and/or specialists for different complaints. Consequently, patient notes and medical histories are often scattered across multiple health care providers and electronic patient management systems are rare (and where they exist, unlinked).

One of the main challenges in implementing the BNR was ensuring adequate early publicity about this national, population-based surveillance system to guarantee full understanding and acceptance of it by both the general population and the medical community. Much of the debate about acceptance of the system, particularly among private health care professionals, involved ethics and confidentiality. In a small population, it becomes even more important that staff adhere to the strict regulations designed to ensure medical confidentiality, as there is an increased likelihood of knowing or even being related to someone whose medical report is being abstracted for data entry. Stringent staff training is not enough; it is also vital to convince private sector physicians, as well as the general public, that their information will be kept strictly confidential. Details about the BNR data communication strategy can be found in [Supplementary material 2](#). Other challenges are briefly described in the Appendix.

### Outcomes from planning studies

Prior to implementation, estimates of the expected workload for each registry component were made based on knowledge gained from earlier one-off

the budget allows for active data collection for a total of about 2 200 events. This works out to about US\$ 148 per confirmed, registered event, or a little more than US\$ 1 per person in the population annually. Salary costs for UWI core staff, and all building costs (including electricity bills, telephone bills, and building maintenance), are met by UWI.

Future surveillance costs are expected to be lower due to the proposed introduction of electronic health information systems (HIS) throughout the island, which should result in a less active data collection system.

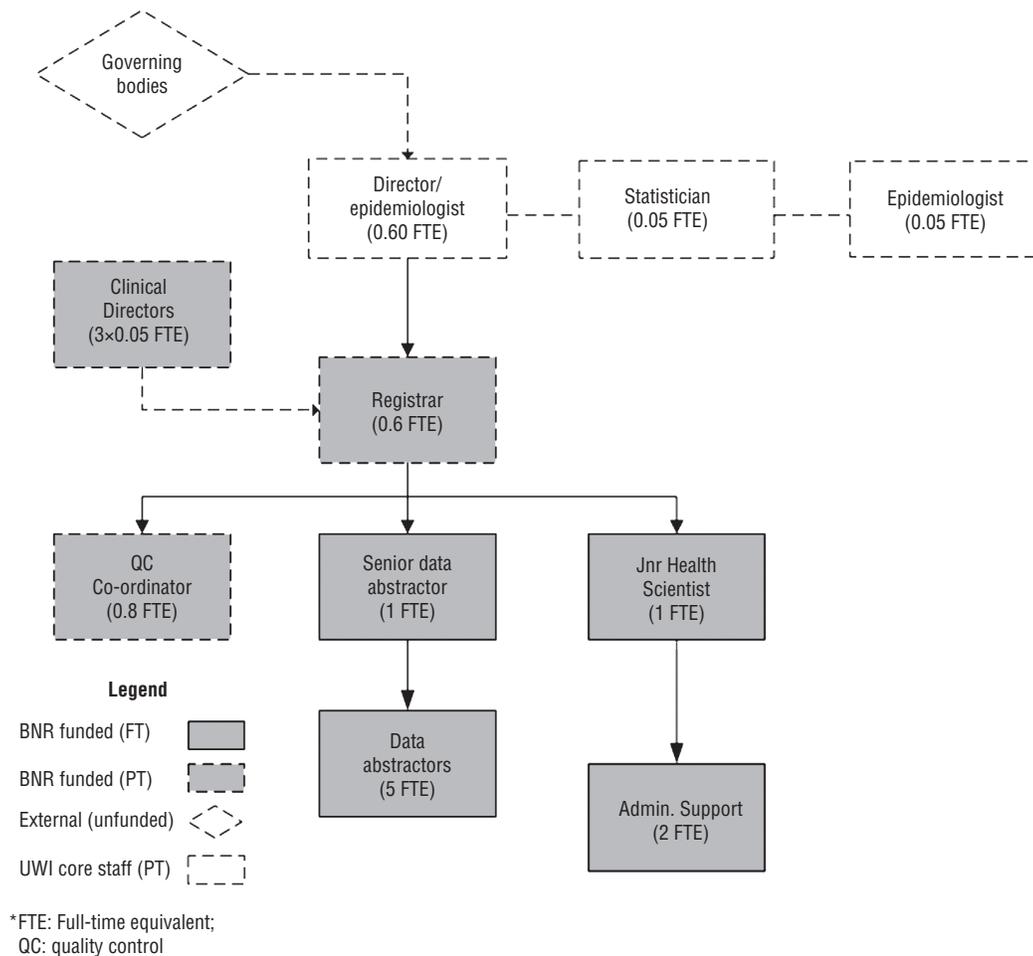
## DISCUSSION

Barbados has successfully implemented a multi-NCD registry that has

now recorded baseline incidence and post-event mortality for acute MI and stroke patients and baseline incidence and survival for cancer patients. As these three diseases contribute significantly to morbidity and mortality on the island, the BNR provides a framework for monitoring trends that can be used to evaluate future health care interventions.

Barbados’ multi-NCD registry may well offer a sustainable disease surveillance model for other limited resource settings. However, the national health care environment informs much of the data collection process. Barbados has a comprehensive public health care system, free at point of contact, consisting of primary, secondary, and tertiary services. There is a network of eight polyclinics providing services to specific regions,

**FIGURE 3. Structure of human resources, including staff from The University of the West Indies (UWI), for the Barbados National Registry for Chronic Noncommunicable Disease (“BNR”), Barbados, 2014**



**Source:** compiled by the authors, based on the registry human resource structure.

research studies or from other countries. The first 12 months of registry data on cancer and acute MI broadly conformed to expectations, but the number of FES events was a little lower and the number of hospitalized acute MI patients a little higher than anticipated (data not shown). The latter outcome can be explained by the ease with which cases can be ascertained using a registry versus routinely collated hospital data. The lower-than-expected number for FES events can be at least partly explained by poor documentation of FES in patient notes. Every year, at least 25% of registered events are documented as FES, but a similar proportion (30%) have no documentation in the hospital record confirming whether the event

was FES. A further 27% are “death certificate only” (DCO) stroke registrants for whom prior event status will always be unknown (i.e., it is not recorded on the death certificate). Another possible explanation for the lower-than-expected numbers for FES is the low proportion of “community only” patients registered with the BNR (fewer than 10% of all stroke events). “Community-only” patients are those with relatively mild events treated without admission to a hospital (data not shown). The labor-intensive, paper-based data abstraction process used in the hospitals often results in community events being underestimated, as registry human resources are mainly consumed by the high in-hospital workload.

The phased introduction of one registry component per year allowed the surveillance team to address and adjust technical staffing and processes over time, resulting in a solid base of trained and experienced technical experts (data collectors and data managers/analysts). Additional skills in both marketing and publicity will be needed to complement the BNR’s strong focus on technical expertise for the registry to realize its full potential.

**Case ascertainment**

For all three registry components (BNR–Cancer, BNR–Heart, and BNR–Stroke), the high case ascertainment ratio (number of suspected patients tracked

through the health care system to obtain a single registration) contributes to the high human resource budget. A working, efficient HIS, even if only within the hospital system, would greatly reduce this data collection (and hence human resource) burden.

## Data

The high out-of-hospital CVD death rate observed from the current data is a clear indication that much work remains to be done in Barbados to 1) educate the public about signs and symptoms of stroke and acute MI and 2) encourage use of emergency transport systems to enable rapid transit to a hospital setting.

The high overall CVD death rate is a cause for concern (about half of all stroke patients and almost three-quarters of acute MI patients registered do not survive to 28 days), despite being only representative of the first five years of the registry. These rates could be due in part to poor ascertainment by the registry for milder cases (thus over-estimating the fatality rate), particularly those being treated only in the community. However, poor public awareness of CVD symptoms and the urgency required for hospital transportation once these symptoms are observed must also play a part, as shown by the high number of patients—particularly for acute MI—who die outside the hospital setting. Less than adequate in-hospital care might also be a contributing factor. This latter issue will be addressed by ongoing analyses of in-hospital CVD management indicators using BNR data. Increased community case ascertainment of CVD patients by the BNR and continued data feedback from the BNR to the public and private medical sectors, together with improvements in health care and population awareness of CVD symptoms, will help determine whether Barbados will achieve WHO's global target of 25% reduction in CVD mortality by 2025 (21).

Data from the CVD registries have proven useful in highlighting areas for health care improvements. Repeated, island-wide seminars for health care professionals addressing these areas have now become part of the registry remit. Continuing medical education credit is provided, with seminar themes identified from registry data. Data from

the BNR have also helped to guide development of the recently implemented stroke unit at the QEH, which opened in August 2013 after conversion of one of the medical wards, as well as the introduction of a hospital acute stroke management protocol. BNR data also underscored the urgent need for a cardiac care unit at the same facility, which was opened in March 2014 but is not yet operational.

The BNR has also been successful in promoting research based on BNR data. Current studies include an investigation of acute stroke management, estimating CVD cost, an estimation of acute bed hospital stay for acute MI patients, and measurement of critical care times, from ambulance callout through hospital arrival to thrombolysis (where appropriate).

## Cost

As with many other disease registries, the main challenge for the BNR is sustainability. A large proportion of funding (> 90%) goes to human resources (Figure 3), and finding personnel, particularly for higher qualified and/or experienced managerial posts, remains an issue for a country like Barbados with a small population. The current level of staffing is still not enough to fully cover the more than 2 000 events abstracted by the BNR team annually, due to the very active nature of the system (e.g., based on the number of registrations in the BNR per year, the estimated optimum ratio of data collector to abstracted events is about 1:200). Therefore, in addition to paid staff, the BNR team also uses volunteers, particularly during holiday periods, to try to increase case ascertainment. At the time this report was written, there was no HIS throughout the medical service in Barbados and the BNR was still a predominantly active, paper-based surveillance system.

The BNR is moving toward more electronic data capture, collecting information from patient notes directly onto laptops or tablets instead of first on paper and then transcribing these to electronic format. Future possibilities to enhance direct electronic data capture from the hospital setting include an on-site link to electronic hospital records where available (currently in the laboratory and emergency departments), and to the stroke unit database.

## Conclusions

The BNR has proven a successful model for NCD surveillance in a small population with limited resources. Despite a high workload for few staff in the early days of the system, there are economies of scale to be gained through shared staff, office space, and resources across registry components. Continued committed political support should result in continued secure and adequate future funding. Other epidemiological transition countries, especially those in the Caribbean region and other SIDS, can learn from the experience reported here. Planning and budgeting for sufficient human resources and an effective communication strategy are key for a strong, sustainable system. The recognition of areas needing health care improvement (such as hospital documentation) has resulted in regular refresher training for health care professionals on the island, which should ultimately improve health care. Data from the BNR have provided a framework for monitoring incidence and survival trends for evaluating future health care interventions and will indicate whether Barbados achieves WHO global targets for reductions in incidence and mortality.

**Acknowledgments.** The implementation of the Barbados National Registry for Chronic NCDs (the BNR) would not have been a success without the hard work and dedication of the BNR team. The authors also thank all of the BNR stakeholders, data sources, and advisors for their support and continued efforts toward improving the process. Most importantly, the authors thank all of the acute myocardial infarction, cancer, and stroke patients and their families for their cooperation and support, especially during the early phases of development of the registry.

**Funding.** The BNR is funded by the Barbados Ministry of Health, National Insurance and Social Security.

**Conflicts of interest.** None.

**Disclaimer.** Authors hold sole responsibility for the views expressed in the manuscript, which may not necessarily reflect the opinion or policy of the RPSP/PAJPH or the Pan American Health Organization (PAHO).

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Manuscript received on 28 July 2015. Revised version accepted for publication on 19 October 2015.

### APPENDIX 1. IMPLEMENTATION OF A NATIONAL REGISTRY FOR MULTIPLE NONCOMMUNICABLE DISEASES IN A RESOURCE-CHALLENGED COUNTRY—MAIN CHALLENGES AND SOLUTIONS, BARBADOS, 2015

Many countries will have data protection laws in force and could experience issues with both the general public and the medical community regarding confidentiality of surveillance data. These are important issues and can be addressed through open discussion with the communities (e.g., through public meetings) and stringent adherence to tight data security processes. In this way, the Barbados National Registry for Chronic Noncommunicable Disease (the BNR) has become quite active in the public domain, promoting the BNR to the community while acting as a resource of public education. It is also important to create alliances with other

private/public health entities, such as the Ministry of Health, national cardiovascular disease (CVD) and cancer nongovernmental organizations (NGOs), etc. The registry can provide NGOs with data, and NGOs can inform the public of the usefulness of the registry in return. It may also be a boost to a registry's national impact to obtain some financial support from the private sector. For example, the BNR appealed to a regional telephony carrier (Digicel), which provided a hotline number for the BNR. This is used by both the general public and the medical community for calling in information, and by the BNR team for maintaining contact with

data abstractors in the field. In return, the Digicel logo appears on the BNR team official shirts below the hotline number, and Digicel is acknowledged for its providing continued support to the BNR during public presentations.

Although these system features may help obtain participation from the community, they may not be enough to obtain full buy-in from the private medical sector. One way toward achieving the latter goal is active involvement by the registry in adapting the national notifiable diseases list to include stroke and acute myocardial infarction, if these conditions are not already included. However, this process will not be particularly meaningful

if there is a lack of either incentives to notify or penalties for not notifying. It is vital that dissemination of data to medical professionals be ongoing and current, so that they are aware of the usefulness of the data. For example, the BNR-Cancer provides a brief quarterly electronic newsletter to all registered physicians on the island, updating them on the status of cancer data. Presentations are also made about the BNR (including highlights of

the latest data) during regular continuing education seminars.

For cancer, if as in Barbados there is no requirement for private laboratories to notify the MoH of every positive result for a malignant neoplasm, working toward updating this requirement would go a long way to improving case ascertainment. This would be especially helpful if private laboratories diagnose a significant proportion of neoplasms nationally.

Finally, to help encourage participation from the main data sources the registry may consider providing them with equipment donations. For example, the donation of a computer for a cash-strapped emergency department can go a long way toward ensuring good relations, especially as CVD registries rely on personnel in these often understaffed departments to provide them with case ascertainment data.

## RESUMEN

### Introducción de la vigilancia nacional de las enfermedades no transmisibles en un país en desarrollo: un modelo para las pequeñas naciones insulares

**Objetivo.** Describir el modelo de vigilancia que se utilizó para crear el primer registro poblacional nacional de múltiples enfermedades no transmisibles en el Caribe (uno de los primeros registros de esta clase en el mundo), la ejecución del registro, las lecciones aprendidas y las tasas de incidencia y mortalidad desde sus primeros años de funcionamiento.

**Métodos.** Esta iniciativa del Ministerio de Salud de Barbados, realizada en colaboración con la Universidad de las Indias Occidentales e impulsada por la limitación de los recursos nacionales, tuvo por finalidad recoger datos prospectivos sobre los casos nuevos de accidente cerebrovascular e infarto agudo de miocardio en todos los establecimientos de atención de salud de este pequeño estado insular en desarrollo del Caribe oriental. El análisis se centró en las fuentes de datos sobre la atención de salud terciaria y de urgencia. La información sobre los casos nuevos de cáncer se obtuvo de manera retrospectiva, principalmente de los laboratorios. Los datos sobre las defunciones se tomaron del registro nacional de mortalidad.

**Resultados.** La introducción progresiva del Registro Nacional de Enfermedades Crónicas no Transmisibles de Barbados se inició con el componente de los accidentes cerebrovasculares en 2008, seguido del componente de infarto agudo de miocardio en 2009 y el componente de cáncer en 2010. Las estimaciones previstas con base en los estudios anteriores fueron en promedio de 378 casos de un primer accidente cerebrovascular, 900 casos de accidente cerebrovascular y 372 pacientes con infarto agudo de miocardio cada año; los datos del registro mostraron un promedio anual cercano a 238, 593 y 349 casos respectivamente. En el 2008, se registraron 1204 casos de cáncer, frente a los 1395 previstos. En función de los datos del registro se definieron los temas de capacitación en salud pública. El éxito de la iniciativa exigió fomentar el apoyo de los profesionales de salud a nivel local y dar a conocer la existencia del registro en toda la isla. Con un gasto cercano a 148 dólares por episodio y 2200 episodios por año, el programa cuesta al Ministerio de Salud alrededor de un dólar por habitante cada año.

**Conclusiones.** Dada la limitación de los recursos absolutos destinados a la salud en los pequeños estados insulares en desarrollo, es preciso analizar la posibilidad de realizar una vigilancia combinada, con el objeto de crear una base nacional de datos fidedignos sobre las enfermedades no transmisibles. Ante la perspectiva de un aumento continuo de la prevalencia mundial, la experiencia en Barbados se ofrece como una "hoja de ruta" destinada a otros países con recursos limitados que planean introducir la vigilancia nacional de las enfermedades no transmisibles.

## Palabras clave

Vigilancia sanitaria; enfermedades cardiovasculares; neoplasias; Indias Occidentales; Barbados