2009 Annual Report

Including progress and updates for Apr-Jun and Jul-Sept 2010

Barbados National Registry for Chronic Non-Communicable Disease

Your registry, Your health

Your Registry, Your Health

Three registries, one mission

Mission Statement

To collect timely and accurate national data on the occurrence of stroke, acute myocardial infarction and cancer, in order to contribute to the prevention, control and treatment of these diseases in Barbados.

Stroke is a sudden neurological event involving either an occlusion or haemorrhage from a cerebral blood vessel.

Acute Myocardial Infarction occurs due to sudden deprivation of the blood supply to the heart muscle (myocardium).

Cancer is a class of diseases in which a group of cells display *uncontrolled growth* (division beyond the normal limits), *invasion* (intrusion on and destruction of adjacent tissues), and sometimes *metastasis* (spread to other locations in the body via lymph or blood).

Contents

Acknowledgements

This report was prepared by the Barbados National Registry for Chronic Non-communicable Disease (the BNR), headquartered at the Chronic Disease Research Centre (CDRC), The University of the West Indies. The BNR is a Ministry of Health initiative, with oversight provided by the National Chronic Non-communicable Disease Commission.

We gratefully acknowledge all patients with heart disease and strokes and their families who contributed to the BNR. This notification process was made possible by the physicians, nursing staff, administrative staff and ancillary personnel within the Queen Elizabeth Hospital, parish polyclinics, geriatric hospitals and private physician offices and diagnostic establishments. Their essential collaboration helps to bring ongoing improvements in stroke, heart attack, and cancer surveillance.

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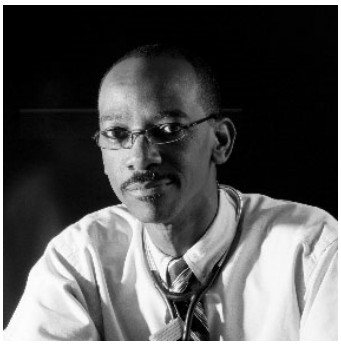


CDRC Director's Summary: Our strategy and vision

The Heads of Government of the Caribbean Community recognized the impact of health as a key determinant of development in the 2001 Nassau Declaration, 'the Health of the Region is the Wealth of the Region'. The primacy of health and development, and recognition of the potential devastating effects of the chronic non-communicable disease (CNCD) epidemic in the region, underpinned the meeting of the Heads of Government of the Caribbean Community in Port of Spain in September 2007. The Declaration of Port of Spain, where there was unanimous agreement that the Region would unite to stop the epidemic of CNCDs, was a bold, unprecedented statement by Caribbean Heads of Government.

The Caribbean has been the region most impacted by CNCDs in this region of the hemisphere. Eight Caribbean territories are ranked in the top 10 countries reporting high mortality attributable to CNCDs throughout the Latin American geographic region; Barbados being ranked the country with the third highest mortality.

The approach to tackling the CNCD epidemic must be multisectoral. Information provided by the Barbados National Registry for CNCDs (the BNR) will be a key tool in the provision of information about the cardiovascular diseases and cancer, the principal causes of ill health and death in our adult population. These data will allow evaluation of disease burden, guide practice and policy for the optimal utilization of scare resources, and allow monitoring and evaluation of interventions. The BNR has already played a major role in the identification of gaps in practice and initiated programmes to train healthcare providers.

As the Caribbean prepares to lead the United Nations Summit on CNCDs in 2011, we can all be justly proud that the BNR will be seen as a major regional success in the programme to tackle CNCDs in the region.

BNR Director's summary: BNR targets and achievements 2009-10

The period 2009–2010 has seen the BNR provide data from the first multi-chronic disease surveillance system in the Caribbean, covering stroke, heart attacks and cancer. The BNR team has established professional working relationships with healthcare institutions across the island in order to provide the data contained in this report.

The BNR has reached its main second-year target of having the second registry, for acute myocardial infarction (acute MI), up and running by 2009. Data from this registry have already proved useful through the valuable feedback on current diagnostic practice and documentation we were able to provide to medical personnel in our first series of acute MI seminars. It is heart-warming to see that the registry is able to respond so quickly to identify needs.

We anticipate that in the coming year we will continue to develop an even more robust structure for chronic disease surveillance and will also continue to identify training needs and organise workshops to address these. In 2010-2011, we will be able to provide 28-day follow-up data for stroke and acute MI events, in addition to a full year of data for BNR-Heart, 2 years of comparable data for BNR-Stroke, and preliminary data for the third registry, which has just been implemented: the BNR-Cancer. A population-based cancer registry which records all occurrences of cancer in a nation is a vital tool against the increasing numbers of malignant disease in our country, and is also an important third component of our registry, which focuses on the three major contributors to illness and death in Barbados as defined by the CMO's report of 2002-3.

The BNR is now a well-established surveillance tool, providing accurate and timely data on the Barbadian population with cardiovascular disease. We look forward to providing both cardiovascular disease and cancer data in 2010-2011, and hope that you enjoy reading this report.

Executive Summary

The Barbados National Registry for Chronic Non-communicable Disease (BNR) has had a highly productive year, producing stroke event data for 2009, and the pilot stage of the acute myocardial infarction (acute MI) registry (the BNR-Heart) providing acute MI event (including sudden cardiac death) data for the last 6 months of 2009.

Summary statistics for all four reporting obligations required by the Barbados Ministry of Health (MoH) have been fulfilled for these two cardiovascular disease (CVD) registries (Table ES1), while the cancer registry is well on its way to being fully operational.

Table ES1. Summary statistics for the Barbados National Registry of Chronic Non-communicable Disease (BNR)

		Acute MI	Stroke (all)	Stroke (first-ever)
Population		134 378	268 756	268 756
No. registrations		182	559	205
Hospital admissions		84	448	202
Deaths		141	222	54
Reporting obligations*	**1**	0.14%	0.21%	0.08%
	2	46.15%	80.14%	98.54%
	3	77.47%	39.71%	26.34%
	4	6 days	4 days	6 days

**Note*: Reporting obligations are defined as: (1) Total number of registrations as a proportion of the population; (2) Total number of hospital admissions as a proportion of registrations; (3) Total number of deaths as a proportion of registrations; (4) Median length of hospital stay (in days).

The 559 stroke registrations (58% female) for 2009 give a crude incidence rate (IR) of all strokes in the Barbados population of 208 per 100 000 (adjusted for the world population, IR = 144 per 100 000).

Of the 559 stroke events, 103 (18%) were identified from death certificates only. Of the remaining 456 (82%) for whom data were abstracted from hospital or physician records, 423 (93%) had received a CT scan or MRI as part of their diagnosis, of whom 65% had their scan within 24 hrs. There were 319 (70%) ischaemic and 70 (15%) haemorrhagic stroke events, of which most (49) were intracerebral.

Sixty of the 456 abstracted stroke events (13%) could not be classified. Almost all (432; 95%) had at least one symptom documented, of which the main symptoms were facial weakness (352; 81%) and slurred speech (286; 66%). Almost half (205; 45%) were first-ever events. Overall, 448 abstracted stroke events (98%) were admitted to the Queen Elizabeth Hospital (QEH), where the median length of stay was 4 days. Of these, 118 (26%) died before discharge. Of those who died in hospital, more than half (71; 60%) were female, and 54 (46%) had not previously had a stroke.

There were 182 acute MI events and sudden cardiac deaths (45% female) in the last 6 months of 2009, giving a crude IR of 135 per 100 000 (134 per 100 000 world-adjusted). Of these, 126 (69%) were classified as definite acute MI, following standard international criteria.

Of the 84 (46%) hospitalised acute MI patients, 50 (59%) had documented evidence of their acute MI from their hospital notes abstracted to the registry. The median length of stay for these patients in the intensive care unit was 3 days; while overall this was 6 days. Most (39; 78%) presented with at least two symptoms, of which the most frequent were chest pain and shortness of breath. More than one-third also had documented in their notes that they were suffering from hypertension (35; 70%), obesity (28; 56%) and/or diabetes (19; 38%).

Current international consensus for acute MI diagnosis includes serial results from cardiac Troponin tests. However, fewer than half of the 50 hospitalised and registered patients (19; 38%) had documented serial cardiac Troponin test results in their records, although two-thirds (33; 66%) had documented evidence of serial CK-MB test results. Most patients (49; 98%) had an available ECG report, and 44 of these (90%) had had serial ECGs performed. Forty-four patients (90%) were given aspirin within the first 24h of hospitalisation, and more than one-third (18; 38%) were also given aspirin on discharge. All but one of the 14 STEMI patients (93%) had been administered thrombolysis.

Of the 182 acute MI and sudden cardiac events registered, 132 (73%) were notified only on their death. Although 34 (26%) of these had the QEH listed as their place of death, information on their events were not obtained for abstraction to the registry. This (non-abstraction) may occur if an initial hospital diagnosis does not include any of the criteria indicating an acute MI, or if the diagnosis was missed by the abstraction team. In both scenarios, however, the attending physician would also have to have failed to notify the event. The BNR is in the process of a case audit for each of these events, to ascertain the reasons for non-abstraction; these results will be in the next BNR report. For the 50 acute MI patients with data abstracted from the QEH, 8 (16%) died before discharge.

Malignant neoplasms are among the leading mortality causes for Barbadian adults, as declared in the CMO's report of 2002-3. The newly established BNR-Cancer will assess the burden from all cancers in the Barbadian population through the registration of all in-situ and malignant neoplasms.

Data collection for the BNR-Cancer began in July 2010 for all cases diagnosed from 2008 onwards. The case report form has been designed, and the International Agency for Research in Cancer (IARC) software will be used for the database. Staff members have undergone initial training and the BNR-Cancer is poised to provide data from only the second national, population-based cancer registry in the English-speaking Caribbean.

The BNR is now a well-established national surveillance system in Barbados, and is the first multi-chronic disease registry in the Caribbean. Data from the registry have already resulted in improved hospital documentation, and a major registry output has been the series of training seminars for medical professionals. These will be held regularly, after using the data to identify training needs. The first series, held in May 2010, covered acute MI diagnosis and documentation. A repeat of this series is planned for late 2010, while another series, focusing on death certificate documentation, is planned for early 2011.

Chapter 1
Introduction and progress report

Introduction and progress report

1.1. Background

Chronic non-communicable diseases (CNCDs) are the leading cause of morbidity and mortality worldwide. The government of Barbados, through its Ministry of Health (MoH), has taken the initiative to be the first country in the Caribbean to tackle these diseases through the creation of a chronic disease surveillance system, the Barbados National Registry for Chronic Non-communicable Disease (the BNR).

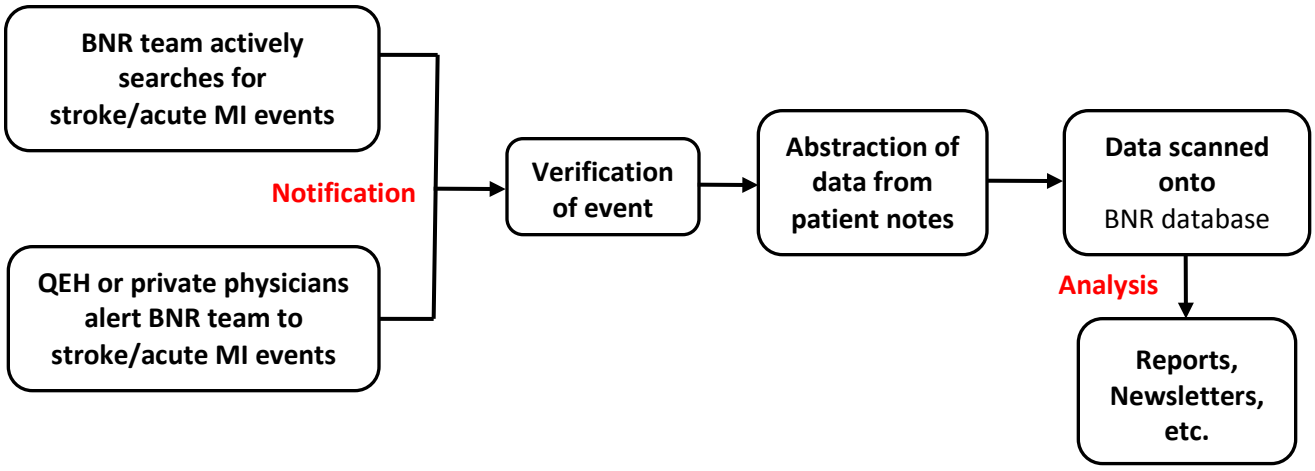
The BNR was established through initial funding from the European Development Fund in 2007.

This national population-based registry collects patient surveillance data from hospital and community records. In addition, face-to-face interviews are conducted with patients at 28 days and 1 year from disease onset. These data will permit the MoH to make evidence-based decisions in national health policy planning. The BNR reporting obligations are outlined below.

- Total number of registrations expressed as a proportion of the population (%)
- Total number of hospital admissions for cancer or cardiovascular events expressed as a proportion of the number of registrations (%)
- Total number of cancer or cardiovascular events discharged and dying expressed as a proportion of the number of registrations (%)
- Average length of hospital stay (in days) for cancer or cardiovascular events

Notification process

The BNR currently uses a mixture of active and passive case-finding. Once events are verified as eligible to be registered, the patient notes are abstracted onto prepared data forms, which are then scanned into a database for analysis and subsequent report-writing and dissemination, as shown below.



1.2. Progress report

General overview

The BNR has managed to accomplish its goals over the past year. These have included improved communication with stakeholders, finalisation of system documentation, and personnel appointments. The registry has now filled all staff positions necessary to provide a comprehensive approach to chronic disease surveillance.

Planning and refinement have been the main focus over the last year, in order to improve the completeness and accuracy of collected data. Two major developments in early 2009 helped to improve the notification process: the BNR notification book and the case-defining form. Each was produced to simplify the process of notification, with the case-defining form also acting as a summary diagnostic sheet for physicians.

BNR data sources

From the inception of the BNR, data have been collected from a wide range of sources, principally the Queen Elizabeth Hospital (QEH). Within the QEH, many different areas and departments provide data, principally the Accident and Emergency, Medical Records, and Death Records Departments, as well as all medical and surgical wards. Data are also collected from the Out-patients, Rehabilitation and Radiology Departments. Data sources outside the QEH include all polyclinics, private physicians, therapists, emergency centres, the national Registry of Births and Deaths, and the Coroner's Office.

The BNR and the private healthcare sector

During 2009-2010 a great deal of effort was made to communicate the role of the BNR and the notification process to the private health sector. This included the creation of the BNR newsletter, '*The Register*', and personal visits to the offices of physicians as well as to community clinics.

A GP survey aimed at community physicians was developed and conducted using an online survey database tool. The survey invited physicians to comment on the BNR notification process (see Summary Report in Appendix A).

IT/database

The documentation for the framework for the combined and updated BNR-CVD database was completed by October 2009. Trinidadian IT consultant and ex-UWI lecturer, Dr David Beckles, is creating a secure database following international best practice, which will make a great contribution to BNR data management retrieval in the future. The first component of this database is currently being tested, and will allow data abstractors to monitor and evaluate pre-registration aspects of stroke and heart attack patients.

Staffing

As of 01 September 2009, the following BNR staff had been recruited:

- Director
- Clinical Director (BNR-Heart)
- Clinical Director (BNR-Stroke)
- Registrar (BNR-Heart and -Stroke)
- Registrar (BNR-Cancer)
- Data Manager
- Data Abstractors
- Data Entry Clerk
- Steno Clerk

Supplemental support is provided by the CDRC statistician. The BNR-Cancer Clinical Director was appointed in April 2010.

Training

An in-house induction programme, related to specific job tasks, has been completed by all new members of staff. BNR-Cancer staff atten-

ded cancer registration training in Trinidad in April 2010.

Governance

External governance is provided through the Technical Advisory Committee (TAC), which meets quarterly, and the Professional Advisory Board (PAB), which meets twice a year (for membership, see Appendix B). These committees allow the BNR to facilitate processes and invite feedback from stake-holders. The meetings assist with dissemination of information and ensuring the utilisation of the key information produced by the BNR.

Internally, weekly CVD meetings occur with the BNR Director, clinical directors, the data abstractors and the data management team. These meetings are chaired by the CVD Registrar, with an agenda driven by data abstractors to facilitate dialogue with the clinical directors. Monthly meetings of the BNR-Cancer Collaborative Working Group (CWG) have been held since May 2010. This group comprises the BNR-Cancer team with input from two external consultants (for membership, see Appendix B).

Publicity

A review of the corporate image of the BNR was conducted in September 2009, and it was agreed that the BNR 'message' ("Your registry, Your health") should be on all correspondence coming out of the BNR. Subsequently, letter-heads were updated with the BNR logo and shirts carrying the BNR message were prepared. Pencils, fridge magnets and book-marks were created to reinforce the message for patrons of BNR booths at public functions. Each of these also carried the BNR website address (http://www.bnr.org.bb), where BNR educational material is posted.

The BNR presence at Caribbean Wellness Day on 12 September 2009 enabled us to provide members of the public with information on strokes and heart attacks, as well as the work of the BNR. The event was captured by the local television channel and newspapers.

Several other opportunities throughout the year gave an opportunity for the BNR to provide booth displays and a presence at various charity fundraisers. This allowed the registry to share information with the general public and healthcare professionals, while showcasing the BNR as a resource centre for information on stroke and acute MI.

Heart and Stroke open day October 2009

Diabetes Global Village, November 2009

As well as having a presence at public events arranged by other organisations, the BNR held an Open Evening of Art and Research in November 2009. Special invitees included medical professionals and featured Guest Speaker Dr Bernadette Theodore-Gandi of the Pan American Health Organisation (PAHO). Art displays with a health theme were viewed for an hour before invitees listened to discussions on

chronic disease in the Caribbean and Barbados, and the progress of the BNR.

BNR Open Evening, November 2009

The inaugural BNR newsletter was released in September 2009. This was aimed at the general public and healthcare professionals, and provides up-to-date information about the progress of the BNR while raising awareness of the role of the registry.

The second issue was printed in February 2010, and focused on the notification process for heart attacks and strokes on the island. The third issue, due at the end of 2010, will focus on the 2009 data presented in this Annual Report.

Challenges

Notification from private physicians continues to prove a challenge, although there has been some improvement after increased office visits by BNR staff. In addition, notification forms are now included with each mailing of the BNR newsletter, to ensure that all physicians have access to these forms.

The major challenge for the BNR-Cancer is the collection of data from private laboratories. Although "malignant disease" is listed as one of the 44 physician-notifiable diseases in Barbados, according to the Health Services (Communicable and Notifiable Diseases) Regulations (1969), the pathology laboratories are governed by the Health Services (Pathological Laboratories) Regulations (1976), which only require notification to the CMO of 24 of these 44 diseases. The list of 24 is found in the Second Schedule of the pathology regulations, and does not include malignancies, thus precluding the collection of valuable data on confirmation of cancer directly from pathology laboratories.

Through collaborations with the Barbados Reference Laboratory, steps are being taken to allow laboratory personnel to attach BNR-Cancer notification forms to all positive cytology reports sent to requesting physicians, prompting them to notify the registry for each case. This is a temporary solution, however, as the BNR anticipates that a revision of the pathology regulations will allow for the notification of all suspected and confirmed cancer cases directly by laboratories island-wide.

Achievements

One of the major BNR achievements has been the use of data from the pilot stage of BNR-Heart to identify and address training needs for medical professionals. A series of three MoH-supported seminars was held, of which the first was in May 2010, focusing on improving diagnosis and documentation of acute MI. All three seminars were expertly chaired by Prof. Trevor Hassell, Chairman of the National Chronic Non-communicable Disease Commission. Dr Joy St John, CMO, provided the welcoming remarks at the inaugural seminar. Drs Stephen Moe, Rudy Delice and Lynda Williams each delivered one session of medical training. PAHO also supported the training by providing the seminar venue.

BNR Seminar, PAHO Headquarters, May 2010

BNR-Stroke

Case definition

Data collection for the BNR-Stroke has been ongoing since July 2008. The stroke case definition (see Definitions for BNR-Stroke in Appendix C) is from the World Health Organisation (WHO)'s stepwise approach to stroke surveillance, which recommends collection of information on stroke patients admitted to heath facilities (Step 1), identifying community-based fatal stroke events (Step 2) and estimating community-based non-fatal stroke events (Step 3).[1]

Documentation and processes

BNR-Stroke standard operating procedures (SOPs) have been finalised and approved. The revised SOPs now reflect software adaptations from the latest version (version 3) of the case report forms. As of February 2010, all 2009 stroke case report forms had been reviewed and scanned into the system. Data cleaning was completed in March 2010.

Expectations

From the previous stroke registry in Barbados, which provided data for 2001-4, the BNR expected to register at least 300 first-ever stroke events per year, for a world-adjusted incidence rate of 85 per 100 000 population per year (95%CI 78-92).[2] Of these, approximately one-third would be non-hospitalised events (i.e. community-treated only).

BNR-Heart

Pilot

The pilot stage for the data collection of BNR-Heart started in May 2009 and was completed in December. This pilot provided information which allowed a review of the data collection processes for acute MI.

Case definition

Extensive testing of the case report form in the pilot stage also highlighted a need for improvements in the diagnosis and reporting of acute MI. A local working definition of acute MI was developed following the expert consensus document on the universal definition of acute MI produced by an international task force and published in 2007.[3] A summary case-defining form was designed, with the objective of improving diagnosis and abstraction of information by consolidating diagnostic data onto one page, using an easy-to-read format. The form was piloted in December 2009 and was further reviewed in May 2010.

Documentation and processes

All BNR-Heart case report forms for 2009 have been reviewed and scanned into the data management system. Data cleaning was completed in April 2010.

BNR-Cancer

According to the CMO's Annual Report for 2002-2003, malignant neoplasms were among the leading causes of morbidity and mortality in Barbadian adults. The BNR-Cancer has been established in order to assess the burden of cancer in Barbados. Data collected will also be used in the development of policies and programmes for the prevention, control and treatment of this disease. The first meeting of the BNR-Cancer CWG, which provides specific cancer-related assistance and advice to the team, took place in May 2010.

Case definition

The BNR-Cancer will register all in-situ and malignant neoplasms as well as select benign tumours (brain and other parts of CNS, pituitary gland, craniopharyngeal duct and pineal gland). Other benign neoplasms and borderline malig-

nancies will be excluded. As in other registries (e.g. the UK), the BNR will adopt a phased introduction to cancer staging. This will begin with summary staging of all registered neoplasms, to be expanded to include TNM (tumour, nodes and metastases) staging of a selection of prominent cancers after the first few years of operation. Data abstraction for this registry began in July 2010 for all patients diagnosed with cancer from 2008 onwards.

Documentation and processes

Minimum dataset and database

Following guidelines clearly defined by the International Agency for Research in Cancer (IARC), essential, recommended and additional variables for the BNR-Cancer minimum dataset were drafted. The proposed dataset was reviewed and finalised by the CWG in June 2010.

An initial notifications database was designed and created by a BNR-Cancer staff member in August 2010. Fully abstracted data will be entered onto the CanReg5 database, which is currently in the process of adaptation for Barbados by BNR-Cancer staff. CanReg5 is the fifth version of CanReg software developed by IARC. It allows for the input, storage and analysis of registry data. Importantly, due to standardised procedures, it allows for comparisons of incidence data with other countries.

Notification and case report forms

Notification of cancer cases is being achieved through active (cases identified and abstracted at source by registry staff) as well as passive case-finding (submission of notification forms by health care professionals). To facilitate passive notification of cancer by physicians, staff members created a cancer notification form. Revisions were made based on input from several specialists across the island and the final version was approved in August 2010.

The BNR-Cancer case report form was developed based on the finalised minimum dataset and was reviewed by the CWG. The form was then distributed to select physicians (oncologists, haematologists, radiologists and pathologists) eliciting their comments. After this review, the forms were tested in the field. They have been further modified and are now in the pilot testing stage. The operations manual was finalised in August 2010.

Staffing

The BNR-Cancer was fully staffed from April 2010, with the appointment of Prof. Patsy Prussia, as Clinical Director. Prof. Prussia is currently the Honorary Consultant Pathologist at the QEH and the recently retired professor in anatomical pathology of the Faculty of Medical Sciences, UWI. Prof. Prussia is lending her expertise in the development of the registry, on-site training of personnel and clinical input for the clarification of difficult cases.

Training

Training for BNR-Cancer staff began in March 2010. Full-time staff studied the literature and began online training in cancer registration from a wide range of sources, including the IARC, Surveillance Epidemiology and End Results (SEER) and the Centers for Disease Control and Prevention (CDC).

In April 2010, the team attended the International Course on *Introduction to Cancer Registration and its Application to Cancer Epidemiology*, organised by IARC and PAHO in Port-of-Spain, Trinidad. The course targeted cancer registry personnel and aimed to introduce international concepts of cancer registration and strengthen capacity in the Caribbean in producing and understanding data

on cancer. The BNR Director, Ms Angela Rose, participated as a trainer on the course and also presented sessions on the progress of the BNR and future plans for the BNR-Cancer. Further to this, plans are in place for BNR-Cancer staff to attend a course on *Principles of Oncology for Cancer Registry Professionals* to be held in Nevada, USA, in November 2010.

Media/publicity

The development of relationships with both public and private sector medical professionals is a priority for the cancer registry. To this end the following strategy has been used.

- Dissemination of letters and draft notification forms to all QEH Heads of Department and the CEO, informing them of the start of the BNR-Cancer
- Dissemination of letters, draft case report and notification forms to selected specialists, requesting feedback on the development of the draft forms
- Dissemination of letters and draft notification forms to all physicians informing them of the BNR-Cancer
- Formal on-site introductions to all QEH Pathology, Radiotherapy, Biochemistry and Haematology Department personnel
- Presentations to/meetings with all private laboratory personnel
- Ongoing visits to private physicians to inform them of the BNR-Cancer
- Liaison with local cancer organisations
- Communication with regional cancer registries to offer support and to seek advice in registry implementation

Data collection

Retrospective data collection started on 01 July 2010, from both the public and private sectors, with the registration of all cancer diagnoses made in 2008.

Data collection has begun with active case finding in the QEH pathology, radiotherapy and haematology departments, as well as from private clinicians across the island.

Chapter 2
Cardiovascular Disease in Barbados, 2009

2.1. BNR-Stroke

Contents

1. Numbers and incidence rates

The number of events reported from a surveillance system gives an idea of the burden of disease in a country, and can be used to inform healthcare requirements. The incidence rate takes the population into account, and may be used to assess trend, or to determine differences within groups, once appropriate statistical tests have been applied.

The period under surveillance for this report was 1 January to 31 December 2009 inclusive (12 months) (Figure 1). The total population of Barbados used for analyses was 268 756.

(a) There were 559 stroke events registered during the reporting period (8 patients had more than one stroke event in 2009).

(b) There were 103 stroke events (18%) notified only at death. The remaining 456 had data abstracted from hospital or clinic records.

(c) Of the 456 abstracted stroke events, 389 (85%) were classified by sub-type. These were ischaemic stroke (319; 70%), intra-cerebral haemorrhage (49; 11%), and subarachnoid haemorrhage (21; 5%).

(d) There were 205 first-ever stroke events registered (64% of the 322 events for whom this information was documented).

Figure 1 shows that there were approximately 46 strokes registered per month in Barbados for 2009. The crude incidence rate was 208.0 per 100 000 population (95%CI 191.1-226.0) for all strokes. For first-ever strokes, this was 76.3 (95%CI 66.2-87.5). The incidence rate standardised to the WHO world population was 144.2 per 100 000 population per year (95%CI 13 1.8-157.8) for all strokes, and 55.0 per 100 000 per year (95%CI 47.3-63.8)* for first-ever stroke events.

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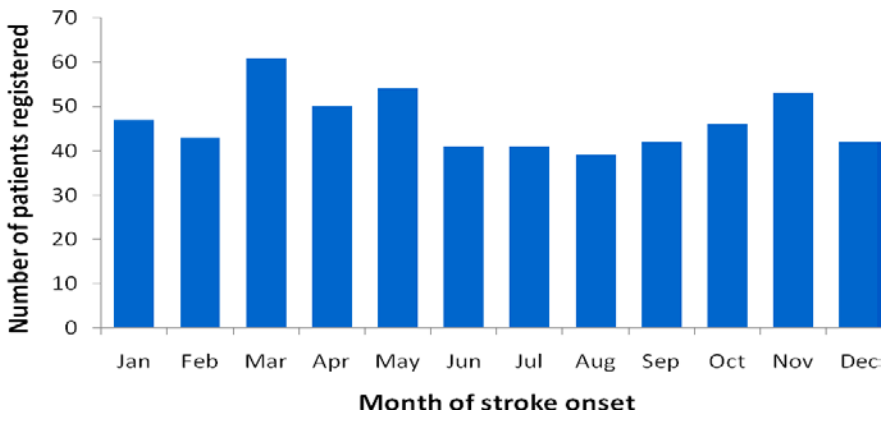
Figure 1. Number stroke events by month of onset, January to December 2009 (N=559)



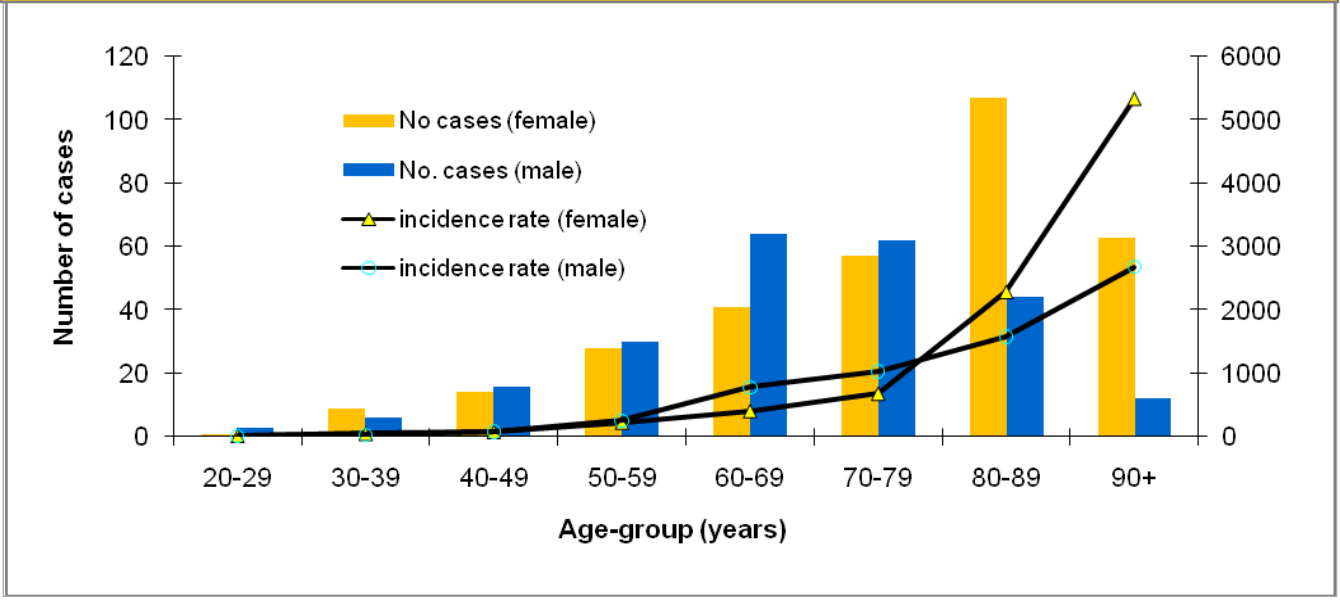
**Note*: directly standardized rates with CI based on the gamma distribution (Fay and Feuer).[4]

2. Demographic characteristics

National surveillance data are usually described by age-group and sex, to give a clinical picture of the case-mix for the disease in a country. Unless statistical tests have been performed, however, any between-group differences reported should not be taken as statistically significant, despite their potential clinical relevance.

In 2009, 322 females and 237 males had a stroke, for overall incidence rates of 230.7 per 100 000 (95%CI 206.2–257.3) and 183.5 per 100 000 (95%CI 160.9–208.4) respectively. The number of stroke events registered by age-group and sex is shown in Figure 2. The incidence per 100 000 population increased with age for both sexes (Figure 2).

Figure 2. Incidence rate of stroke per 100 000 population in Barbados, 2009, by age-group and sex



Key points

- ≈46 strokes/month occur in Barbados
- Greater number of strokes reported for women than men in those aged ≥80 yrs
- Number and incidence rate of first-ever stroke events lower than expected based on data from previous registry

3. Presentation and diagnosis

3.1. Diagnostic tests used

A stroke event is generally diagnosed clinically, with imaging tests providing information for stroke sub-type classification. The primary imaging tests used in stroke diagnosis in Barbados are the CT and the MRI (see Appendix C).

The remaining data in this report will focus on the 456 hospitalised or community-treated stroke events, for which data were abstracted from hospital or clinic records.

Of the 456 registered stroke events, 424 (93%) received a CT scan, while <1% had an MRI. Of the 408 (96%) for whom this information was available, 276 (68%) had their scan within 24h and 125 (31%) were scanned within 7 days.

Fewer than 10% (35) of stroke patients went on to receive a secondary diagnostic test (cerebral angiography, carotid ultrasound, or lumbar puncture).

3.2. Classification of stroke subtypes

Stroke sub-typing provides a classification of the type of stroke (see Appendix C), which is important for determining treatment.

The majority of registered strokes in 2009 were classified as ischaemic (319; 70%) with only 70 (15%) haemorrhagic strokes (Table 1).

Table 1. Classification of stroke subtypes

Stroke subtype	Number	%
Ischaemic stroke	319	70
Intracerebral haemorrhage	49	11
Subarachnoid haemorrhage	21	5
Unclassified/Unspecified*	60	13
Not documented	7	1

*Unclassified strokes reflected either that (1) no CT or medical autopsy was available at time of diagnosis; or (2) the stroke was not able to be clinically specified.

3.3. Presenting symptoms and signs

The symptoms experienced by a patient are usually a part of the presenting complaint, causing them to seek medical attention. Presenting signs, however, are those noted in the patient's record by the physician as having been observed in the patient at first clinical examination. Although often similar, signs do not necessarily correspond with symptoms.

There were 432 patients (95%) with at least one symptom documented. The most common symptoms recorded were facial weakness (352 78%) and slurred speech (286; 63%). Ten percent of patients (43) had no recorded signs. Most (254; 56%) experienced at least two signs. The commonest signs were limb weakness (381; 84%) and slurred speech (216; 47%).

3.4. Length of hospital stay

There were 448 patients with stroke (98%) admitted to the QEH during 2009. Of these, 354 (78%) were admitted for more than 24 hrs, while 94 (21%) were discharged within 24 hrs from the Accident and Emergency Department (A&E) without admission to a hospital ward. Median length of hospital stay was 4 days (range 0–377 days). For the 10 patients (2%) who received intensive care, median length of stay on the ICU was 6 days (0-155 days).

4. Mortality

Of the 448 admitted patients, 118 (26%) died before discharge from the QEH. Six patients (1%) did not have vital status documented.

4.1. In-hospital stroke deaths (N=118)

Most patients who died before discharge (116; 97%) had been hospitalised for at least 24 hrs. A CT scan was performed on 113 (96%) of those who died in hospital, while 1 was referred for an MRI scan. Eighty-seven (74%) had at least two symptoms documented. Table 2 compares selected characteristics between the 118 patients who died before discharge from hospital with those 331 who were alive at discharge.

The Glasgow coma scale (GCS) is used to assess the severity of brain impairment in somebody with a brain injury, and is the sum of scores given for eye-opening, verbal, and motor responses. The highest score (15) indicates no impairment and a score of 8 or less indicates severe impairment.

Initial GCS scores were documented for 112 (95%) of the 118 patients who died before discharge. Of the 112, approximately one-third (39; 35%) had severe impairment (Table 2). In contrast, 17 (5%) of the patients who were still alive at discharge had severe impairment based on this scale (Table 2).

Table 2. Selected characteristics of stroke patients who were alive at discharge vs those who died before discharge from hospital				
	Alive at discharge (N=331)		Died before discharge (N=118)	
	No.	(%)	No.	(%)
Median age (range)	70 years (24-98)		79 years (33-101)	
Median length of stay (range)	3 days (0-377)		8 days (0-251)	
Females	182	(55)	71	(60)
First-ever stroke	150	(45)	54	(46)
Total GCS score *Total tested*	246	(74)	112	(94)
<9*	17	(7)	39	(35)
9-14	90	(37)	52	(46)
15†	139	(57)	21	(19)
Stroke sub-type**				
Ischaemic	238	(72)	80	(68)
Intracerebral haemorrhage	28	(8)	21	(18)
Subarachnoid haemorrhage	16	(5)	4	(3)
Unclassified	48	(15)	12	(10)

*Severe impairment

†No impairment

**One event from each vital status category was missing data on stroke sub-type. Percentages were therefore calculated out of N-1 for each category.

2.2. BNR-Heart

Contents

1. Numbers and incidence rates per 100 000 population

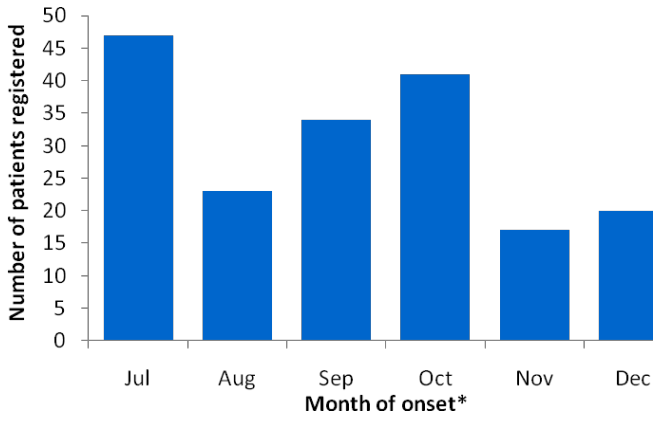
The number of events reported from a surveillance system gives an idea of the burden of disease in a country, and can be used to inform healthcare requirements. The incidence rate takes the population into account, and may be used to assess trend, or to determine differences within groups, once appropriate statistical tests have been applied.

The period under surveillance for acute MI for this report was 01 July 2009 to 31 December 2009, inclusive (6 months) (Figure 1).

There were 182 acute MI and sudden cardiac deaths recorded during this period. Of the 182 events, 126 (69%) had a definite acute MI diagnosis (see Appendix C for definitions). Fifty-three (29%) were sudden cardiac deaths for whom data were obtained from death records only (i.e. patient notes were not seen), and 3 (2%) were defined as possible acute MI (Figure 2). Of the 126 definite MIs:

- 50 (40%) had data abstracted from the QEH
- 19 (15%) were classified as non-ST elevation MIs (NSTEMI)
- 14 (11%) were classified as ST elevation MIs (STEMI)

Figure 1. Number of patients with acute MI by month* of onset, July-December 2009 (N=182).

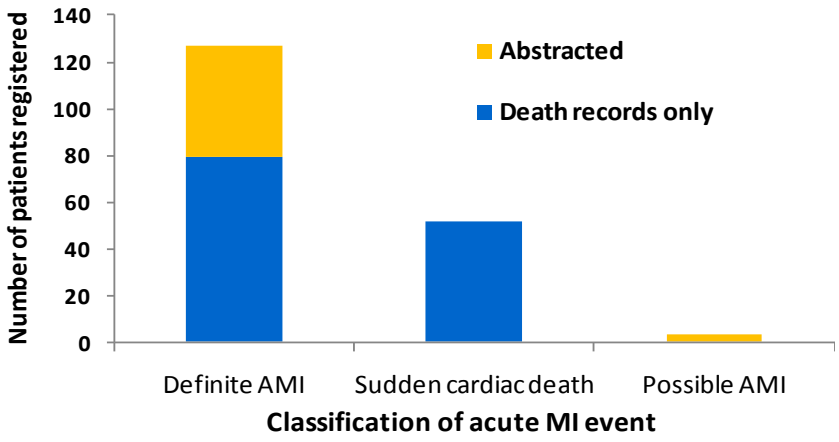


**Note*: for events recorded from death records only, month of death was used as month of onset.

The crude incidence rate for acute MI in Barbados for 2009 was 135.1 per 100 000 population (95%CI 116.2-156.2). The incidence rate standardized to the WHO world population (N=181; one patient did not have age recorded) was 134.3 per 100 000 (95%CI 76.0-105.0).*

*Note: directly standardized rates were calculated with CI based on the gamma distribution, as described by Fay and Feuer (1997).[4]

Figure 2. Number of patients with acute MI by definition of event, July-December 2009 (N=182).



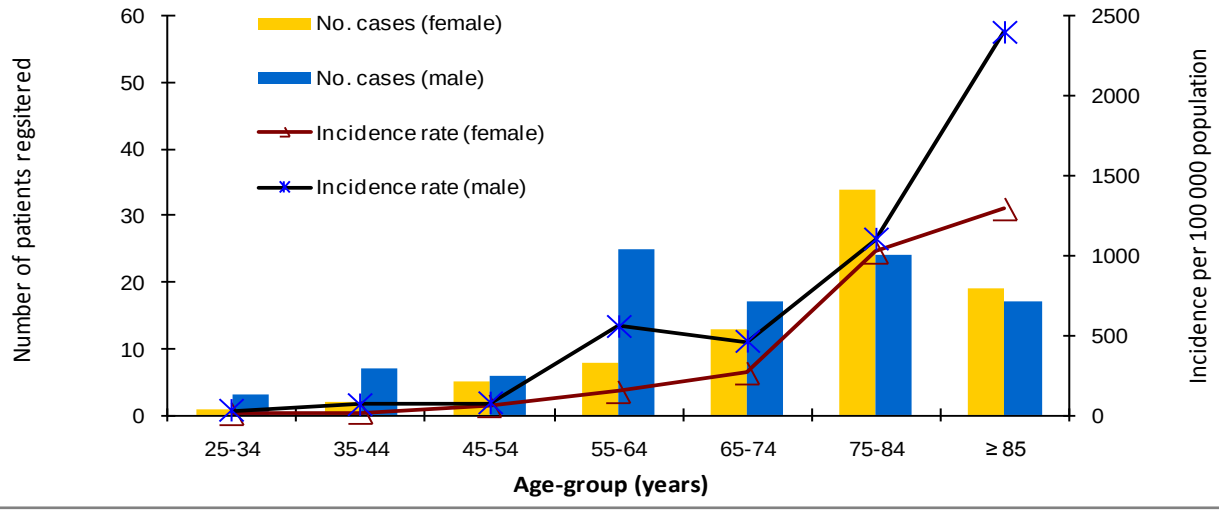
2. Demographic characteristics

National surveillance data are usually described by age-group and sex, to give a clinical picture of the case-mix for the disease in a country. Unless statistical tests have been performed, however, any between-group differences re-ported should not be taken as statistically significant, despite their potential clinical relevance.

In 2009, there were 82 female and 100 male patients with acute MI in Barbados, for an overall incidence rate of 117.2 per 100 000 women (95%CI 93.2-145.5), and 154.4 per 100 000 men (95%CI 125.6-187.8). Although the proportion of men <55 years with an acute MI was about twice that for women (19% vs 10%), these data represent only 6 months of data and numbers are too small to draw any firm conclusions.

The incidence increased with age for both sexes, with most of the reported events in men occurring among those aged 55 years and older, while most reported acute MI events in women were in those aged 65 years and over (Figure 3).

Figure 3. Incidence rate of acute MI per 100 000 population in Barbados, 2009, by age and sex



Key points

- Data presented for the last 6 months of 2009
- ≈8 acute MIs/month abstracted from QEH
- ≈13 acute MIs/month notified only at death
- More acute MIs in men than women <75 yrs
- More acute MIs in women than men ≥ 75 yrs
- Higher incidence rate in men of all age-groups
- 19% of acute MIs in men were <55 yrs
- 10% of acute MIs in women were <55 yrs

3. Presentation and diagnosis

3.1. Hospitalisation and ambulance use

Of the 182 patients with acute MI events, 84 (46%) were hospitalised at the QEH. Of these, 50 (59%) had data abstracted from patient records, while 34 were found through death record information only.

Forty-six of the 50 patients with abstracted data had documented information on ambulance use (92%). Of these, 31 (67%) had used this service, with 30 (60%) having clearly documented dates and times of ambulance arrival and hospital admission. Median ambulance time to hospital from pick-up for these patients was 27 min.

Eighteen patients had clearly documented ambulance arrival and chest pain onset times; for these, median time from onset to admission was 2.5 hrs. Excluding four patients for whom arrival at hospital was more than 12 hrs after symptom onset, the time from chest pain onset to ad-mission ranged from 37 min to 10 hrs 13 min.

3.2. Length of hospital stay

Of the 50 patients with abstracted information, 2 (4%) were missing information on hospital stay, as the discharge form had not been completed. For the remaining 48, median length of stay was 6 days (range 0–44 days). For the 16 patients (33%) who were in the ICU, the median length of stay was 3 days (range 1-5 days).

3.3. Presenting symptoms

Of the 50 patients with abstracted information, 39 (78%) presented with two or more symptoms. The most frequent symptoms (affecting more than 50% of patients) were chest pain and shortness of breath (Table 1).

Table 1. Presenting symptoms for acute MI patients in Barbados, July-December 2009 (N=50)

Symptom	Number	%
Chest pain	45	90
Shortness of breath	29	58
Sudden vomiting	17	34
Palpitations	13	26
Sudden dizziness/ vertigo*	12	24
Headache	6	12
Cough	6	12
Light-headedness, nausea /malaise	5	10
Numbness (limbs, fingers)	2	4
Orthopnoea	2	4
Decreased responsiveness	2	4
Dyspnoea	2	4
Other†	6	12

*Missing information from 1 patient for this symptom.

†Weakness, fatigue (1), slurred speech (1), swollen ankles (1), impaired vision (1), PND (1), abdominal pain (1).

Key points

- > 1/2 acute MI patients died outside hospital
- 2/3 acute MI patients used ambulance service
- Ambulance time from patient pickup = 27 min
- 1/3 acute MI patients treated in ICU
- Median length of stay 3 days (ICU); 6 days (ward)

3.4. Prevalence of known risk factors

Known risk factors are characteristics for which prior research has shown an association with acute MI. These can be biological (e.g. having a current co-morbidity, or having had a prior CVD event), lifestyle-related (e.g. smoking), or even family-history-related (e.g. having a family member who has had a prior CVD event).

Table 2 shows the prevalence of known CVD risk factors among the 50 patients with abstracted data. The most common risk factor for these patients was hypertension (35 patients; 70%), followed by obesity (28; 56%) and diabetes (19; 38%). None of the patients reported a prior coronary intervention.

There were only two patients (4%) with no known CVD risk factors recorded, and seven (14%) with a single risk factor recorded. Thirty-five patients (70%) had between two and four risk factors, and the remaining six (12%) had more than four.

Table 2. Prevalence of known risk factors among acute MI patients, July-December 2009 (N=50)

Risk factor type	Risk factor	Number	Percentage
Prior CVD event/disease	Prior acute MI	8	16
	Prior IHD	8	16
	Prior stroke	2	4
Current co-morbidity	Hypertension	35	70
	Obesity	28	56
	Diabetes	19	38
	Hyperlipidaemia	11	22
Lifestyle-related	Alcohol use	13	26
	Smoking	9	18
	Drug use	3	6
Family history	Sibling (acute MI)	3	6
	Mother or father (acute MI)	4	8
	Mother (stroke)	1	2

3.5. Diagnosis

The diagnosis of an acute MI can be complex; combining clinical judgement with biochemical marker and ECG results (see Appendix C). Current international consensus diagnostic guidelines[3] include serial tests for the cardiac biomarker Troponin (an indicator of recent heart muscle damage) over a certain period. Prior to Troponin, the creatine-kinase (CK-MB) tests were in common use. The results of these tests, as well as the times at which they were performed, should be recorded in the patient's notes.

Of the 50 patients for whom data were abstracted from hospital records, there was information on cardiac biomarkers for 45 (90%). Of these, two-thirds had documented evidence of three CK-MB tests, while fewer than half had documented evidence of three Troponin biomarker tests (Table 3).

Table 3. Number of patients with serial (up to three) cardiac biomarkers

	1		2		3	
	No.	**%**	**No.**	**%**	**No.**	**%**
CK-MB	45	**90**	45	**90**	33	**66**
Troponin	27	**54**	23	**46**	19	**38**

Of the 45 having cardiac biomarker tests, fewer than one-third had the times of the tests clearly documented in their notes (Table 4). An ECG report was available for 49/50 patients (98%), of whom 44 (90%) had had serial ECGs performed.

Table 4. Median times taken for cardiac biomarkers									
	Time from onset to first biomarker			Time from first to second biomarker			Time from second to third biomarker		
	Mins	**Hrs**	**Range (h)**	**Mins**	**Hrs**	**Range (h)**	**Mins**	**Hrs**	**Range (h)**
CK-MB	495	**8**	3-29	436	**7**	4-28	480	**8**	6-14
Troponin	210	**4**	1-9	420	**7**	4-15	360	**6**	-

Note: N varied from 11 (onset to first CK-MB) to 2 (second to third Troponin, both taking 6h).

The ischaemic region on the ECG for the 50 patients with abstracted data is shown in Table 5. Most patients (31; 63%) were diagnosed with an ECG category of ST segment elevation (Table 6). There were 19 patients (39%) and 18 patients (37%) with ST segment depression and T wave inversion, respectively (Table 6).

Table 5. Ischaemic region on ECG*(N=50)		
Region	**Number**	**%**
Anterior	14	29
Anterolateral	12	24
Inferior	9	18
Posterior	6	12
Septal	5	10
Lateral	4	8
Anteroseptal	4	8
Right ventricle	1	2
Inferior lateral wall	1	2
Undetermined/Unknown	19	39

Note: patients can have more than one region listed.

Table 6. ECG* category		
ECG category	**Number**	**%**
ST segment elevation	31	63
ST segment depression	19	39
T wave inversion	18	37
Pathological Q waves	9	18
LVH**	8	16
Normal	7	14
Non-specific ST-T changes	3	6
Right BBB	3	6
Left BBB	2	4
Old MI	2	4
Other¥	11	22
Unknown	1	2

Note: patients can have more than one category listed.

**LVH: Left ventricular hypertrophy.

¥Other: Sinus tachycardia (2); atrial fibrillation (2); AV block (2); Inferior wall MI right branch (1); PVCs (1); Ventricular tachycardia (1).

Key points

- Most acute MI patients (70%) also have hypertension
- >1/3 acute MI patients are also obese
- >1/4 acute MI patients also have diabetes
- Very poor documentation of cardiac biomarker tests and results, especially timing of tests

4. Treatment and outcomes

4.1. Routine medication

The initial treatment of an acute MI relates specifically to the underlying cause of the problem. For NSTEMI events, the initial treatment normally focuses on preventing the constricted artery from becoming completely blocked, e.g. through "blood-thinning" medication (e.g. aspirin). Best practice guidelines[5] suggest that five oral medications are given to patients with an acute MI diagnosis during hospitalization and following discharge (see Appendix C).

For all 50 events, information was available on aspirin use, either before hospitalisation (chronic: 14 patients; 29%), on arrival or within 24 hrs (acute: 44 patients; 90%) or on discharge (18 patients; 37%) (Table 7).

The two other most commonly prescribed drugs (for >1/3 of patients) in the acute stage were heparin LM and Plavix. The two most commonly prescribed at discharge were statins and Plavix (Table 7).

Table 7. Routine medication* for acute MI patients in Barbados, July-December 2009

Medication	Chronic use		Acute use†		On discharge	
	No.	%	No.	%	No.	%
Aspirin	14	28	43	86	18	42
Warfarin	1	2	4	8	3	7
Heparin SC	0	0	13	26	-	-
Heparin LM	0	0	39	78	1	2
Clopidrogel (Plavix)	6	12	35	70	10	24
Statin	8	16	33	66	14	33
Insulin	3	6	16	32	6	14
GI prophylaxis	2	4	31	62	5	12

**Note*: Some patients may use the same medication before, during and/or after admission. Information on beta-blockers, ACE Inhibitors and angiotensin receptor drug use was collected, but as of the preparation of this table, had not been fully collated.

†On arrival or within 24 hrs of admission.

4.2. Reperfusion

For STEMI events, the treatment aim would usually be to open the artery as quickly as possible in order to restore normal blood flow, either through "clot busting" medication (e.g. thrombolytics) or angioplasty.

Of the 14 patients diagnosed with STEMI, thrombolysis was administered to 13 (93%).

4.3. Hospital complications

Of the 50 abstracted events, 11 (22%) had a clearly documented complication. Of these, 8 (73%) had a single recorded complication, and the remaining 3 had 2 or more (Table 8).

4.4. Mortality

In-hospital deaths

(a) Of the 50 hospitalised patients with complete information abstracted, 8 (16%) had died before discharge from hospital.

(b) There were 138 patients (76%) registered with the BNR after finding a record in the national register of deaths indicating acute MI, or sudden cardiac death within a context of heart disease. Of these, six matches were found to fully abstracted data. Of the unmatched 132, 34 (26%) had place of death listed as the hospital.

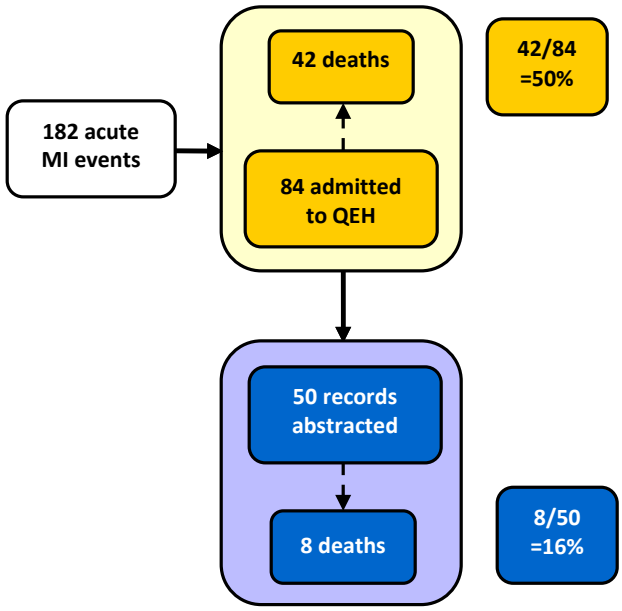
(c) The overall in-hospital case fatality rate could therefore have ranged from 16% to 50% (8+34/84); see Figure 4. Excluding 11 of these, who had been classified as "sudden cardiac deaths", the in-hospital case fatality rate from confirmed acute MI was estimated at 31/73 (42%).

(d) The overall number of deaths (from death records and abstraction) shows that there were 141 deaths out of a total of 180 acute MI events and sudden cardiac deaths (two patients had vital status unknown). Of these, 61 (43%) had a Coroner's report, while 73 (52%) had been medically certified.

Table 8. Hospital complications*			
Hospital complication	**Number**	**% (all; N=50)**	**% (of all those who recorded a complication; N=11)**
Post MI chest pain/angina	7	14	64
Infection**	3	6	27
Hypotension post thrombolysis	2	4	18
Postural hypotension	2	4	18
Ventricular aneurysm	1	2	9
Cardiac arrest	1	2	9
Cardiogenic shock	1	2	9
Congestive cardiac failure	1	2	9

**Note:* Some patients had more than one complication.
**LRTI (1), UTI (1), pneumonia (1).

Figure 4. Schematic showing potential range of in-hospital death rates from acute MI and sudden cardiac death in Barbados, 2009



Key points

- Almost all patients were given aspirin, heparin or Plavix in the acute stage (within 24 hrs of arrival)
- About 1/10 patients had a documented hospital complication
- In-hospital death rate estimated to be between 16% and 50%

Chapter 3
Conclusions and recommendations

Conclusions and recommendations

The BNR has now been operational since July 2008 with the advent of the BNR-Stroke, and this Annual Report presents results from the first complete year of data (2009) for this registry. In addition, results are given from the first 6 months (July-December 2009) of operation of the BNR-Heart, which registers all events of sudden cardiac death and acute MI in Barbados. The BNR-Cancer became operational in April 2010 and started collecting data from July 2010 for all cases diagnosed from January 2008 onwards.

It is not possible to make any conclusions based on trend in this Annual Report, as data cover only the first year for stroke and the first 6 months for acute MI.

In general, for good coverage of all cases of stroke, acute MI and cancer nationwide, the BNR needs to become a household name in Barbados. Plans are underway for increased marketing and publicity of the BNR, to help both the medical community and the general public to understand the tremendous re-source of this chronic disease registry.

Stroke

The Barbados Registry of Strokes (BROS) collected information on first-ever stroke events for the period 2001-3,[2] providing a benchmark of expected data for the BNR-Stroke. From BROS data, the BNR-Stroke expected to register >300 first-ever strokes each year, for a world-adjusted incidence rate (IR) of 85 per 100 000 population per year (95% CI 78-92).[2] The expected mean age for first-ever strokes was 72 years, and it was anticipated that 58% of these would be female. Approximately one-third of all first-ever strokes registered in BROS were notified from the private sector.

When compared with these expected BROS figures, the first-ever stroke patients registered with the BNR-Stroke in 2009 had very similar age and sex characteristics (mean age 72 years; 57% female). The number of first-ever strokes registered (205) was lower than expected based on numbers observed in the BROS study. Similarly, the world-adjusted IR for first-ever stroke in 2009 (55 per 100 000 per year; 95%CI 47-64) was also lower than expected. However, for 234 stroke events (42%), there was no documentation to indicate whether the patient had had a prior stroke (including 103 patients registered at death).

The number of stroke events reported in 2009 from the private sector (eight) was also much lower than expected. (Based on the BROS expectation of one-third of all cases, this should have been at least 100.)

Population-level surveillance of chronic disease shows that there are usually only small fluctuations in numbers from year to year, with larger increases or decreases in incidence being observed over longer periods taking several years. The most plausible explanation for the 'missing' 100 first-ever stroke registrations in the relatively short period since the BROS study, therefore, is that they were due to a combination of factors: some stroke events were not reported to the registry by the private sector, and others were patients who lacked documentation about prior stroke status in their hospital records.

Two of the main targets for the coming years of the registry are therefore to improve the uptake of notification from the community, principally the private sector, and to improve documentation of stroke status in patient records.

For a population-based registry such as the BNR to be truly representative, data must be collected from the entire population, i.e. both hospital- and community-based patients. We recommend more inclusion of the private sector in medical professional seminars and training, and direct targeting of this group to encourage them to notify cases to the registry.

Acute MI

Of the 50 acute MI patients with abstracted data, only about one-third had all three serial Troponin test results and very few had documented evidence of cardiac biomarker times documented in their notes. As part of the current diagnosis of an acute MI involves knowledge of the changes in cardiac Troponin over time, it is important that, where appropriate, acute MI patients have serial test results for this cardiac biomarker clearly documented in their notes, with accompanying test times.

Results for cardiac biomarker CK-MB, however, were documented in 90% of acute MI patients. It is possible that many physicians use this cardiac biomarker, which formed part of earlier acute MI definitions and is more readily available on the island. Cardiac Troponin is often not available in Barbados and, further, there is no local population reference level available. This is the threshold indicating the value above which an individual has probably suffered from a heart attack. We recommend that a population reference level for cardiac Troponin be estimated for the Barbadian population and that this biomarker be made more readily available for physicians in Barbados. We also recommend further training for medical professionals in acute MI diagnosis.

The overall in-hospital death rate from acute MI was estimated at somewhere between 16% (for the 8/50 abstracted records) and 50% (if including patients notified at death only, with the hospital listed as their place of death). This is higher than in-hospital deaths documented in other countries (as an example, Canadian in-hospital acute MI deaths are around 11%).[6] However, these data only cover 6 months, from the pilot stage of the BNR-Heart, and should be interpreted with caution.

For example, for the 34/84 "death registry only" deaths with the hospital listed as their place of death: the dates of death placed them in the correct time-frame (between July and December 2009), but it is possible that some of them had actually had their cardiac event before July, but died during or after July. In addition, it is difficult to determine whether someone with "sudden cardiac death" on their death certificate actually had their event caused by an acute MI (although sudden, unexpected cardiac death is part of the international consensus criteria used for acute MI definition).

Most (74%) of the registered deaths did not have the hospital as their place of death, making it difficult to trace their records in any attempt to audit their cause of death. Death record data can only be obtained at least 3 months after death and, at this stage, even for patients who had been hospitalised, tracing their records would be difficult.

We recommend further training for medical professionals in death certification documentation. In addition, we recommend an audit to compare the diagnoses in the hospital notes with the cause(s) of death on the death certificate for all of the in-hospital deaths from acute MI which occurred in July-December 2009, but which were not captured by the registry. The results of this audit will be in the next BNR Quarterly Report.

Our data show that almost 1/5 of acute MI events occur in men <55 years. In contrast, in Oxfordshire, data from 1994-5 show that <1/10 male patients were <50 years.[7] However, this may simply be a reflection of the relatively

younger Barbadian population. In addition, although we should not be complacent about the proportion of younger men in our acute MI case-mix, we should not draw any firm conclusions from only the first 6 months of registry data.

Cancer

Data collection for the BNR-Cancer began in July 2010; analysis of 2008 data will be the main feature of the 2010-2011 annual report.

The BNR-Cancer has been actively collecting information from public and private institutions across the island on patients diagnosed since 2008. We will now also focus our efforts on collaborations with all cancer organizations, in an effort to spread the word about the work of the BNR-Cancer to include new collaborations with insurance companies, a valuable data source for cancer registries, especially when patients seek treatment overseas.

The Pathology Act (1976) currently prevents the BNR-Cancer from collecting data directly from private laboratories across the island, as it has not yet been modified to reflect the requirements of the later Notifiable Diseases Act, which update the notifiable diseases list to include all malignancies. Although we can still receive notifications from physicians, as cancer is primarily a disease which is confirmed by laboratory testing, we recommend that the Pathology Act (1976) be updated to allow laboratory staff to notify the MoH and the BNR.

At the time of writing this updated report, data had been collected from almost 3000 suspected cancer diagnoses in 2008, from about 12,400 reports. The retrospective nature of this registry means that these have to be checked and validated by the team before abstraction can begin. An estimate of the expected number of registrations for 2008 will be presented in the next BNR report.

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Chapter 4
Strategic Objectives 2010-2011

Strategic objectives 2011

General

- Review and update (as appropriate) all case report forms and SOPs (April 2011)
- Test and pilot the new database with information for 1 month in March 2011; go live in April 2011
- BNR staff to be trained in the use of the new database (March-April 2011)
- Increase hits to the BNR website (March 2011)
- Provide at least two newsletters in 2011
- Create more opportunities for data sources to be included in the data abstraction process, e.g. through invitation to lunchtime briefings

BNR-Stroke

- Seek to improve community medical practitioner participation in the BNR
- Revise stroke case report form to reflect a more accurate subtype classification (March 2011)
- Provide a series of training workshops for hospital and community-based physicians on stroke diagnosis and treatment throughout 2011
- Present a comparison of the first and second years' data analyses at an international conference (end 2011)

BNR-Heart

- Provide a second series of acute MI diagnosis training for private physicians and hospital medical personnel who were unable to attend the first course (mid 2011)
- Provide a training workshop for nursing staff on the ECG procedure in partnership with the Heart and Stroke Foundation of Barbados (early 2011)
- Perform an audit of the hospital records and death certificate information for the acute MI in-hospital deaths which were not registered
- Present a comparison of the first and second years' data analyses at an international cardiology conference (end 2011)
- Increase the efficiency of data abstraction between hospital admission and discharge

BNR-Cancer

- Provide advanced training for staff (November 2010)
- Fine-tune the CanReg5 database provided by IARC (early 2011)
- Provide a series of training workshops for hospital- and community-based physicians on death certificate documentation (early and mid 2011)
- Provide an estimate of expected numbers of cancer diagnoses in 2008 for the next BNR report
- Analyse 2008 data (Sept 2011)
- Submit an abstract on the first year's data analyses to an international cancer conference (late 2011)

Chapter 6
Appendices

Appendix A: Notification survey summary

BNR Notification Survey summary report, December 2009

During the Technical Advisory Committee on 24 June 2009, it was agreed that a short project to ascertain why BNR notification process appeared not to be working would be conducted. Thirty General Practitioners would be interviewed using an online questionnaire.

Data Collection

An electronic survey was conducted using the free online software program "Survey Monkey". The survey was constructed thorough eight questions aimed at soliciting the views of potential users on the best avenue of data collection and notification processes in the community setting. A list of email addresses from the Barbados Association of Medical Practitioners (BAMP) was used. There were 268 emailed questionnaires, from which there were 30 responses.

Notification Survey Results

Of the 30 respondents, 73% noted that they understood the BNR to be a chronic disease surveillance system, although 20% believed it to be a clinical research study. It was anticipated that not all individuals would have notified a case of acute MI or stroke, and this was verified, as 60% stated that they were not able to notify due to the following reasons:

- Assumption that QEH would notify the case and therefore they did not need to
- Not feeling educated enough to do so
- Time consuming
- Not aware that both acute MI and stoke were to be notified

There was a split regarding the best notification process in clinical practice, with the most effective method viewed as a secure web-based notification site, followed by notification forms.

In order to extract the data from the patient notes the preference (57%) was for a BNR data abstractor to collect the BNR forms once completed by the practice doctor or nurse, (28%) would prefer that the data abstractor visit and review the notes.

General feedback of BNR data by email or a short bulletin was preferred by 43%, and a regular newsletter was preferred by 23%. Interestingly, 10% thought that a webinar or BNR website was acceptable. Two-thirds were happy for a senior member of the BNR team to visit them to discuss any concerns (38% were not).

Overall

The results suggest that the BNR needs to be flexible in its approach to community practices. The request for communication feedback suggests that secure electronic methods of feedback would need to be established.

For practice personnel who prefer to complete the BNR case forms themselves there would need to be a period of training and possibly simplification of the forms to ensure that errors are minimised. The low response rate is due in part to a large number (130) of failed email addresses; obtaining an up-to-date email listing of GPs would ensure more adequate coverage and hence a more representative sample.

Appendix B: Advisory groups' membership lists

The Technical Advisory Committee of the BNR

Name	Affiliation
Dr Michael Campbell (Chair)	Chairman, Ethics Committee, QEH
Dr Euclid Morris	Lecturer – Faculty of Medical Sciences
Mr John Grace	President, Diabetes Association of Barbados
Ms Hyacinth Grimes	President, Myeloma, Lymphoma & Leukaemia Foundation of Barbados
Dr Stephen Moe	President, Heart &Stroke Foundation of Barbados
Mr Aubrey Blackett	President, Cancer Support Services
Ms Yvonne Lewis	Vice President , Cancer Support Services
Dr Dorothy Cooke-Johnson	Honorary Secretary, Barbados Cancer Society
Ms Harriet Brathwaite	Corporate Communication Specialist, Sagicor
Dr Kenneth George	Senior Medical Officer of Health, MoH
Mr Mitchell Clarke	Chief Nursing Officer, MoH
Ms Louise Bobb	DSS (Ag), QEH
Dr RK Shenoy	Consultant Radiotherapist, QEH
Prof. David Corbin	Consultant Neurologist, QEH; Clinical Director, BNR – Stroke
Dr Rudolph Delice	Head of Dept of Medicine, QEH; Clinical Director, BNR – Heart
Prof. Patsy Prussia	Honorary Consultant Pathologist, QEH; Clinical Director, BNR – Cancer
Prof. Anselm Hennis	Director, CDRC
Ms Angela Rose	Director, BNR
Ms Tracey Blackman	Data Manager, BNR
Mrs Gina Pitts	CVD Registrar, BNR
Ms Rhea Harewood	Cancer Registrar, BNR

The Professional Advisory Board of the BNR

Name	Affiliation
Prof. Trevor Hassell (Chair)	Chairman of the National Commission for Chronic Non-Communicable Diseases
Dr Bernadette Theodore-Gandi	Caribbean Programme Co-ordinator, PAHO/WHO
Dr Joy St John	Chief Medical Officer, MoH
Dr Kenneth George	Senior Medical Officer of Health, MoH
Dr Dexter James	CEO of the QEH
Dr Richard Ishmael	Consultant cardiologist, QEH
Dr RK Shenoy	Consultant radiotherapist, QEH
Prof. David Corbin	Consultant Neurologist, QEH; Clinical Director, BNR – Stroke
Dr Rudolph Delice	Head of Dept of Medicine, QEH; Clinical Director, BNR – Heart
Prof. Patsy Prussia	Honorary Consultant Pathologist, QEH; Clinical Director, BNR – Cancer
Prof. Anselm Hennis	Director, CDRC
Ms Angela Rose	Director, BNR
Mrs Gina Pitts	CVD Registrar, BNR
Ms Rhea Harewood	Cancer Registrar, BNR

The BNR – Cancer Collaborative Working Group

Name	Affiliation
Prof. Patsy Prussia	Honorary Consultant Pathologist, QEH; Clinical Director, BNR – Cancer
Dr Lynda Williams	Consultant, Barbados National Cancer Study
Dr Suzanne Smith Connell	Consultant Radiation Oncologist, QEH
Prof. Ian Hambleton	Statistician, Chronic Disease Research Centre
Ms Angela Rose	Director, BNR
Ms Tracey Blackman	Data Manager, BNR
Ms Rhea Harewood	Cancer Registrar, BNR
Ms Jacqueline Campbell	Cancer Data Abstractor, BNR

Appendix C: Definitions

1. Statistics

An **incidence rate** is the number of new disease events occurring in a specified population during a year, usually expressed as the number of events per 100,000 population at risk. That is,

Incidence rate = (New events / Population) × 100,000

The numerator of the incidence rate is the number of new disease events; the denominator is the size of the population. The number of new events may include multiple events occurring in one patient. In general, the incidence rate would not include recurrences (where recurrence is defined as a presentation to the healthcare system within a certain period of the initiating event).

An **age-adjusted rate** is a weighted average of the age-specific rates, where the weights are the proportions of persons in the corresponding age groups of a standard population. The potential confounding effect of age is reduced when comparing age-adjusted rates computed using the same standard population.

A **mortality rate** is the number of deaths, with the disease (stroke or AMI) as the underlying cause of death, occurring in a specified population during a year. Mortality is usually expressed as the number of deaths due to the disease per 100,000 population. That is,

Mortality rate = (Disease Deaths/Population) × 100,000

The numerator of the mortality rate is the number of deaths; the denominator is the size of the population.

2. BNR-Stroke

The BNR uses the WHO stroke definition of a focal or global neurological impairment of sudden onset, lasting more than 24 hrs (or leading to death), and of presumed vascular origin.

Global impairment refers to patients with depressed consciousness or coma. The definition excludes:

- Coma of systemic vascular origin
  - Shock
  - Stokes-Adams' syndrome
  - Hypertensive encephalopathy
- Transient ischemic attacks (TIA)
- Subdural haemorrhage
- Epidural haemorrhage
- Poisoning
- Symptoms of trauma

Ischaemic stroke

Stroke symptoms which are known to originate from an occlusion (blockage) of cerebral arteries.

Intracerebral haemorrhage

Stroke symptoms which may arise from the bleeding from intracerebral arteries.

Subarachnoid haemorrhage

Stroke symptoms which arise from bleeding from intra-cranial arteries, resulting in blood arising between the two membranes which surround the brain.

CT (computerised tomography) and **MRI** (magnetic resonance imaging) refer to two of the most common tests which may be used to diagnose a stroke event, and to classify its subtype.

3. BNR-Heart

The working definition for acute MI in Barbados is based on the current universal and epidemiological definitions. The 99th percentile upper reference limits (URL) for the levels of specific cardiac biomarkers in a healthy Barbadian population are not available at this time.

Definite acute MI

A definite acute MI is defined as:

- Diagnostic cardiac biomarkers *(serial measurements ~6-9 hrs apart, level elevated above lab URL, rise/fall in levels demonstrated*) with **at least one** of:
  - Typical or atypical acute MI symptoms and/or signs of cardiac failure (*Killip Class II-IV*)[2]
  - Imaging changes *(New wall motion abnormalities)*
  - Positive ECG (STE/NSTE/New LBBB/ Path Q waves)[3]
- Sudden (unexpected) cardiac death
  - Post CABG or PCI with cardiac biomarkers 5X and 3X laboratory upper reference limit (lab URL)[4] respectively
  - Pathological findings of acute MI

Probable acute MI

A probable acute MI is defined as:

- Positive ECG with one of the following:
  - Cardiac symptoms and/or signs plus missing biomarkers OR inadequate biomarkers (*samples measured > 10hrs apart OR no serial measurements*)
  - Equivocal biomarkers (*only 1 biomarker elevated>lab URL OR only 1 with rise/fall not in the setting of clinical cardiac ischaemia OR non-ischaemic causes of biomarker elevation present*)

Possible acute MI

A possible acute MI is defined as:

- Equivocal biomarkers plus cardiac symptoms and/or signs OR non-specific ECG (*ST depression 0.5-1.0mm , T wave inversion or flattening in leads with dominant R waves*)
- Positive ECG plus missing OR inadequate biomarkers

Treatment guidelines

Current best practice suggests five oral medications are often given to patients during hospitalization and following discharge with an acute myocardial infarction diagnosis all with the aim of decreasing mortality and protect heart muscle:

- **Aspirin,** to lower the risk of another event
- Additional **blood thinners** (e.g. Clopidrogel), to lower the risk of another event and to prevent clots from building up on stents
- **Beta-blockers,** to lower the risk of abnormal heart rhythms and to promote healing of heart muscle damage
- **ACE inhibitors or angiotensin receptor blockers,** to promote healing of the heart and to lower the risk of another heart attack
- **Statins,** to lower cholesterol and the risk of another heart attack

[2]Class II= crackles, S3 gallop and elevated JVP; Class III=frank pulmonary oedema; Class IV=cardiogenic shock.

[3]NEW findings in at least two contiguous leads of either evolving ST elevation (ST elevation ≥1.0mm), or evolving non-ST elevation (horizontal/down-sloping ST depression ≥1.0mm and/or T inversion ≥1.0mm with R wave prominence or R/S ratio>1) or evolving pathological Q waves (≥0.04s and > ¼ of R wave amplitude) or LBBB.

[4]Threshold levels for biomarkers=upper lab reference limit for AST, CK-MB, CK-MBm and > 0.1µg/L for Troponin.