A Comparative Study of the Quality and Availability of Health Information used to Facilitate Cost Burden Analysis of Diabetes and Hypertension in the Caribbean

C Cunningham-Myrie, M Reid, TE Forrester

ABSTRACT

Objective: *Non-communicable Diseases (NCDs) are leading threats to health and well-being in the Caribbean. A study was undertaken in the latter part of 2005 to compute the economic burden of diabetes mellitus and hypertension within the Caribbean Community and Common Market (CARICOM). This report critiques the quality and availability of health information which can be used to facilitate cost burden analysis of diabetes mellitus and hypertension.*

Methods: *A form was developed and disseminated to obtain epidemiological and health service utilization data. Subsequent visits were made to seven CARICOM member countries to collect the data.*

Results: *The results revealed (i) a number of deficiencies in the reliability and validity of the data received, in particular, those needed to facilitate the analysis of cost-specific complications such as ischaemic heart disease, cerebrovascular disease, chronic renal failure, hypertensive and diabetic retinopathy and peripheral circulatory complications; (ii) data management systems in hospitals were not linked to facilitate generation of cost-effectiveness estimates and other information required to compare options for health investment; (iii) despite repeated attempts by regional governments to develop/strengthen Health Information Systems within the Caribbean, sustainability has been significantly hampered by human, material and financial resource constraints and ongoing monitoring and evaluation is generally poor.*

Conclusion: *There are deficiencies in the quality and availability of health information to facilitate cost burden analysis of hypertension and diabetes mellitus in the Caribbean. Strong commitment from CARICOM governments will be necessary to address these concerns if economic evaluations are to be undertaken more frequently as part of the effort to reduce the morbidity and mortality from these diseases.*

Estudio Comparativo de la Calidad y Disponibilidad de la Información Sobre la Salud Usada para Facilitar el Análisis del Nivel de Costos de la Diabetes y la Hipertensión en el Caribe

C Cunningham-Myrie, M Reid, TE Forrester

RESUMEN

Objetivo: *Las enfermedades no comunicables (ENC) se cuentan entre las principales amenazas a la salud y el bienestar en el Caribe. Se llevó a cabo un estudio hacia finales de 2005, con el fin de computar la carga económica de la diabetes mellitus y la hipertensión dentro de la Comunidad y el Mercado Común del Caribe (CARICOM). Este reporte constituye un análisis crítico de la calidad y disponibilidad de información sobre la salud, que puede ser usada para facilitar el análisis del nivel de costos de la diabetes mellitus y la hipertensión.*

Métodos: *Se desarrolló y distribuyó un formulario para obtener datos acerca de la utilización de servicios de salud y servicios epidemiológicos. Posteriormente se realizaron visitas a siete países miembros de CARICOM con el propósito de recoger datos.*

From: Tropical Medicine Research Institute, The University of the West Indies, Kingston 7, Jamaica.

Correspondence: Dr C Cunningham-Myrie, Tropical Medicine Research Institute, The University of the West Indies, Kingston 7, Jamaica. E-mail colette.cunninghammyrie@ uwimona.edu.jm

Resultados: *Los resultados revelaron (i) algunas deficiencias en cuanto a la confiabilidad y la validez de los datos recibidos, en particular los necesarios para facilitar el análisis de las complicaciones costo-específicas, tales como la enfermedad cardíaca isquémica, la enfermedad cerebrovascular, el fallo renal crónico, la retinopatía hipertensiva y diabética, y las complicaciones circulatorias periféricas; (ii) los sistemas de administración de datos en los hospitales no estaban conectados para facilitar la producción de estimados de costo-efectividad y otras informaciones requeridas para comparar las opciones de inversión para la salud; (iii) a pesar de reiterados intentos de los gobiernos regionales por desarrollar y fortalecer los sistemas de información de salud en el área del Caribe, su sostenimiento ha sido obstaculizado significativamente a causa de restricciones en cuanto a recursos humanos, materiales y financieros, y por el hecho de que el monitoreo y la evaluación actuales son generalmente pobres.*

Conclusión: *Existen deficiencias en la calidad y disponibilidad de información sobre la salud, en cuanto a facilitar el análisis del nivel de la magnitud del costo de la hipertensión y la diabetes mellitus en el Caribe. Será necesario un fuerte compromiso por parte de los gobiernos del CARICOM para abordar estos problemas, si se ha de emprender evaluaciones económicas con mayor frecuencia, como parte del esfuerzo por reducir la morbilidad y la mortalidad por estas enfermedades.*

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INTRODUCTION

The Non-communicable Diseases (NCDs) have emerged in the Caribbean, as elsewhere, in an environment where substantial shifts in dietary patterns and dietary energy intake along with physical inactivity precipitate sustained positive energy balance and thus weight gain. This nutrition transition is associated with an epidemiological transition in which infection and malnutrition recede and are replaced as leading causes of death by the chronic diseases.

An extensive literature search has provided overwhelming evidence of this growing burden of chronic diseases, in particular the cardiovascular diseases and diabetes mellitus, within the Caribbean region (1–27). Mortality from chronic diseases has dominated for at least three decades. Table 1 highlights the leading causes of death for both gender and all ages in the Caribbean Epidemiology Centre (CAREC) member countries. Since the 1980s, the NCDs were always the top five causes of death which is inclusive of many of the cardiovascular diseases (hypertension, coronary artery disease and stroke) and diabetes. It is only in the past few years that AIDS has risen to be in this ranking (27).

Table 1: Eight leading causes of death in CAREC[a] member countries

	1985	1990	1995	2000
1.	Heart disease	Heart disease	Heart disease	Heart disease
2.	CVD[b]	Cancers	CVD[b]	Cancers
3.	Cancers	CVD[b]	Cancers	CVD[b]
4.	Diabetes	Diabetes	Diabetes	Diabetes
5.	Hypertension	Hypertension	Hypertension	AIDS
6.	Accidents	ARI[c]	Accidents	Hypertension
7.	ARI[c]	Accidents	ARI[c]	Accidents
8.	Nutritional deficiencies	Diseases of urinary System	AIDS	Assault

[a]CAREC = Caribbean Epidemiology Centre
[b]CVD = Cerebrovascular disease
[c]ARI = Acute respiratory tract infections

The Caribbean Commission on Health and Development (CCHD) was established in 2003 to provide guidelines for action to increase investment in health in the countries in the Region. The magnitude of the threats caused by these diseases especially obesity, hypertension and diabetes, was presented in a comprehensive report to the Caribbean Community (CARICOM) Heads of Government at the twenty-sixth meeting held in St Lucia in July 2005. The report included an analysis of the economic burden estimates for diabetes and hypertension. Calculations were done only for Jamaica for 2002 and amounted to approximately $US 58 million. (26). These estimates comprised direct and indirect costs, although data constraints limited the calculation of indirect costs to productivity loss only.

Given the aforementioned limitations in methodology and regional coverage, a larger study was undertaken in the latter part of 2005 to compute the economic burden of diabetes and hypertension for seven countries within the CARICOM. The human capital approach and prevalence-based approach were used in the economic analysis. The robustness of the economic estimates so derived is contingent on the accuracy of the epidemiological and health service utilization data retrieved. This, in turn, is a function of the health information systems (HIS) in countries selected for study. These may be defined as systems which integrate data collection, processing, reporting and use of the information necessary for improving health service effectiveness and efficiency through better management at all levels of health services (28). Systems which provide timely, accurate and relevant information facilitate sound decision making on effective health policies, services and behaviours. Informed citizens are able to hold their governments accountable for the allocation and use of health resources. Regionally and internationally, information from the HIS is used to monitor

trends in disease prevalence and control, in results-based management of development assistance programmes and to advocate for increased financing for health (29, 30).

This report critiques the quality and availability of health information to facilitate cost burden analysis of diabetes and hypertension in the Caribbean. The report does not focus on the methodology or results of the economic analysis.

METHOD

Data required

A data collection form was developed in September 2005. Two broad categories of information were sought: a) epidemiological data and b) health service utilization data for the most current year(s) available that was nationally representative. Items necessary for the economic analysis but not included in the data collection form were obtained from published data from the World Health Organization (WHO), Pan American Health Organization (PAHO), local health organizations and academic literature.

Within the English-speaking Caribbean, persons with diabetes, hypertension and their related complications may be treated at either the primary or secondary levels of healthcare. For primary care health institutions, information is collected reflecting health service utilization *ie* caseload and workload by diagnosis. Coding using the International Classification of Diseases – 10 [ICD–10] (31) is not done at this level and so the data tend to be aggregated *ie* include complications of the underlying cause. (The ICD has become the international standard diagnostic classification for all general epidemiological and many health management purposes). At the secondary care level, hospitals generate case abstracts for hospital discharges for diabetes, hypertension and their related complications which are coded using ICD-10. These data are usually transmitted vertically to the individual countries' regional health bodies and/or the Ministries of Health. Additionally, in the case of discharges due to death, data may/may not be simultaneously transmitted to the agency responsible for vital registration. [For some countries, registration of death is solely the responsibility of the relative of the deceased]. The CAREC retrieves mortality data on member countries from vital registration authorities. Ministries of Health possess information on hospital-related deaths. The PAHO also receives country-specific mortality data from vital registration authorities through its local offices. However, it is not unusual for PAHO to compute estimates if reliable and valid data are unavailable from a particular country.

To facilitate comparability of standardized data, only morbidity and mortality data which were coded according to ICD-10 were used for the purposes of this study. These reflected the underlying causes of diabetes and hypertension and their main complications for which interventions were available. Specific data requested included:

Epidemiological data

- Total and gender-specific population by age group
- Total and gender-specific mortality rates of diabetes and hypertension by age group
- Total and gender-specific prevalence rates of diabetes and hypertension by age group
- Age-specific cases of diabetes without and with complications (including renal, eye and peripheral circulatory) coded using the International Statistical Classification of Diseases (ICD)-10 codes E10.9, E11.9; E10.2, E11.2; E10.3, E11.3; E10.5 and E11.5
- Age-specific cases of hypertension without and with complications (including renal and eye) coded using the ICD-10 codes I 10, I 12.0 and H 35.0
- Age-specific cases of ischaemic heart disease and cerebrovascular disease coded using the ICD-10 codes I 20-25 and I 60–69

Health service utilization

- Annual public and private sector outpatient consultation costs for diabetes and hypertension
- Annual public and private sector hospital-stay costs for diabetes and hypertension
- Annual public and private sector hospital costs for diabetes-related lower limb amputations
- Unit costs for investigative procedures recommended annually for patients with diabetes and hypertension according to guidelines for monitoring these conditions in Jamaica.

Data collection

Country visits were conducted between October and November 2005 after the data form had been disseminated to each country through its Chief Medical Officer and in the case of Trinidad and Tobago via the local Pan American Health Organization (PAHO) office. The lead time, prior to visits for all countries, was a minimum of two weeks (except for Guyana where it was only a week). The visit to each country lasted an average of two working days. Apart from the retrieval of the data forms, interviews were also conducted with key persons involved in the clinical management and health information systems pertaining to diabetes, hypertension and their related complications.

Countries selected were Antigua and Barbuda, Bahamas, Barbados, Guyana, Jamaica, St Lucia and Trinidad and Tobago. These countries were thought to be representative of the diversity of population size, geographic variability, economic wealth and ethnocultural differences that exist within the 15-member CARICOM. The required health data were retrieved from a number of different sources which provided national data from routine and *ad hoc* collection systems. These included national vital statistics, registration of deaths, national census, health service statistics from the public and private sector, disease specific registries, sample surveys, special research studies and case report

summaries.

RESULTS

None of the participating countries had completed the data collection form in time for the country visits. Reasons were varied and included receipt of the form just prior to the visit, lack of communication to the assigned health staff about the purpose of the study and impending visit, staff shortages and time constraints. However, the face-to-face consultations afforded the opportunity to explain the background of the study and clarify aspects of the data collection instrument. In most cases, final submissions were done electronically, subsequent to the visit.

Epidemiological data

Basic demographic data and disease-specific mortality rates were available for all countries as is shown in Table 2a. In particular, the mortality rates for all countries except Jamaica were obtained from CAREC for the year 2000. (The study period did not allow adequate time to cross- check all the data from CAREC and the primary sources within each country). In Jamaica's case, routine submission of mortality data to CAREC had stopped prior to 2000 due to several constraints that limited the quality of data reported. These included, among other things, inaccuracies in a) the cause of death b) coding of deaths and c) deficiencies in the process and quality of registration of deaths. Instead, submission was done after validation of the data. The most accurate mortality data for Jamaica were obtained from a study by McCaw-Binns *et al* (32) for the years 1996 and 1998. This study determined mortality rates by reviewing data received from the multiple sources which routinely collect information on selected deaths.

Reliable estimates of the prevalence of diabetes and hypertension were obtained from Bahamas, Barbados, Jamaica and St Lucia. The information came from special surveys namely the Bahamas Living Conditions Survey [2001] (33), Barbados Eye Study [1988–1992] (8, 16), Jamaica Lifestyle Survey [2001] (34) and the International Collaborative Study on Hypertension in Blacks 1994–98 (22, 23). A community survey had been conducted in Trinidad and Tobago between 1977 and 1986 (3) but the information was thought to be too dated to have current relevance. Antigua and Guyana reported no previous prevalence studies.

Tables 2a and 2b also summarize the morbidity data *ie* data on hospital discharges collected in the respective countries. For Bahamas and Jamaica, the data were obtained from the Ministries of Health but in the case of Barbados, directly from the Queen Elizabeth Hospital, the island's sole public hospital.

The Ministries of Health in Trinidad and Tobago and Guyana were unable to provide information on most of the requested coded diagnoses as they only had ICD-10 morbidity group codes. For example, they were able to give

Table 2a: Epidemiological data collected from seven CARICOM member countries

Epidemiological data	Antigua and Barbuda	Bahamas	Barbados	Country Guyana	Jamaica	St Lucia	Trinidad
Total population (year 2004)	68 000	325 170	271 000	797 000	2 650 934	150 000	1 322 221
Mortality rates per 100 000 (year 2000) – Diabetes mellitus	37.3	34.6	84.1	100.8	56.4[a]	55.8	96.7
– Hypertension	52.6	35.2	48.0	64.4	40.0[a]	17.3	31.3
Prevalence rates (%) – Diabetes mellitus	N/A[b]	3.3	17.5	N/A[b]	7.2	6.1	N/A[b]
– Hypertension	N/A[b]	9.3	55.4	N/A[b]	20.8	25.9	N/A[b]
DIABETES Morbidity rates per 100 000 (n)		**Year 2003**	**Year 2002**	**Year 2002**	**Year 2004**	**Year 2004**	**Year 2002**
Diabetes without complications ICD – 10 code E 10.9 and E 11.9	N/A[b]	18.9 (60)	N/A[b]	4.32 (33)	82.9 (2198)	26.7 (40)	N/A[b]
Diabetes with renal complications ICD – 10 code E 10.2 and E 11.2	N/A[b]	0.3 (1)	6.0 (16)	0.13 (1)	1.5 (40)	1.3 (2)	N/A[b]
Diabetes with eye complications ICD – 10 code E 10.3 and E 11.3	N/A[b]	0.3 (1)	57.2 (154)	0.13 (1)	1.2 (31)	0.7 (1)	N/A[b]
Diabetes with peripheral circulatory complications (including amputations) ICD – 10 code E 10.50 and E 11.5	N/A[b]	9.2 (29)	N/A[b]	0.13 (1)	18.7 (496)	40.7 (61)	N/A[b]

[a] Year 1998

[b] N/A – Not available

Table 2b: Epidemiological data collected from seven CARICOM member countries

Epidemiological data (Cont'd)	Country						
	Antigua and Barbuda	Bahamas	Barbados	Guyana	Jamaica	St Lucia	Trinidad
HYPERTENSION Morbidity rates per 100 000 (n)		Year 2003	Year 2002	Year 2002	Year 2004	Year 2004	Year 2002
Essential hypertension (no complications) ICD – 10 code I 10	N/A[a]	29.7 (94)	681.8 (1834)	78.7 (601)	323.7 (8581)	84.7 (127)	74.3 (972)
Hypertension with renal complications ICD – 10 code I 12.0	N/A[a]	22.1 (70)	47.2 (127)	1.05 (8)	24.9 (660)	2 (3)	N/A[a]
Hypertension with eye complications ICD – 10 code H 35.0	N/A[a]	0 (0)	0.37 (1)	0.39 (3)	0.3 (7)	0 (0)	N/A[a]
Other related morbidity data	N/A[a]	36.3 (115)	179.9 (484)	14.5 (111)	91.1 (2415)	37.3 (56)	242.7 (3174)
Ischaemic Heart disease ICD – 10 code I 20 – 25							
Cerebrovascular disease ICD – 10 code I 60 – 69	N/A[a]	75.2 (238)	160.2 (431)	37.8 (289)	164.1 (4350)	40 (60)	116.7 (1526)

[a]N/A – Not available

totals for the ICD-10 group E10 to E14 which summarizes the data for diabetes and its complications, but stated it would be too difficult or impossible to provide disaggregated data on the requested subcategories E10.9, E11.9 *etc*. In Guyana, the disaggregated data were eventually obtained from the individual public hospitals which had maintained a handwritten index card system grouped according to specific ICD 10 codes. Antigua's main hospital, Holberton hospital had a similar handwritten index card system. Their health records unit had ceased routine reporting of morbidity data to its Ministry of Health for an unspecified period and the staff interviewed was unable to give a reason for this practice.

In St Lucia, the morbidity data were supplied by its two main hospitals, the larger Victoria hospital (150-bed capacity) located in the capital city of Castries to the north of the island and St Jude hospital (88-bed capacity) a semi-private facility located to the south of the island. The smaller hospital had a computerized database and in most instances reported more cases for each diagnosis than the larger hospital raising questions of the reliability of the data from the latter (Table 3).

Tables 2a and 2b also illustrate that data on the specific codes pertaining to diabetes and hypertension with eye complications were either unavailable or grossly under-reported by all countries (in many instances single-digit figures). The explanation given was that most cases were being managed by eye specialists in the private sector. For the other codes where data were unavailable or under-reported, the health records staff of the respective countries intimated that the case summaries completed by the physicians often did not reflect the link of the underlying disease with its complications.

Table 3: Morbidity Data – St Lucia (Data given for the most current year available)

Condition	All ages (n)	Year and source
Diabetes		
Diabetes without complications	66	2002 Victoria Hospital
ICD – 10 code E 10.9 and E 11.9	27	2004 Victoria Hospital
	13	2004 St Jude Hospital
Diabetes with renal complications ICD – 10 code E 10.2 and E 11.2	2	2002 Victoria Hospital
Diabetes with eye complications	2	2002 Victoria Hospital
ICD – 10 code E 10.3 and E 11.3	1	2004 St Jude Hospital
Diabetes with peripheral circulatory complications (including amputations) ICD – 10 code E 10.50 and E 11.5	61	2004 St Jude Hospital
Hypertension		
Essential hypertension (no complications)	46	2002 Victoria Hospital
ICD – 10 code I 10	35	2004 Victoria Hospital
	92	2004 St Jude Hospital
Hypertension with renal complications ICD – 10 code I 12.0	3	2004 St Jude Hospital
Hypertension with eye complications ICD – 10 code H 35.0	0	2004 St Jude Hospital
Other related morbidity data		
Ischaemic Heart disease	4	2002 Victoria hospital
ICD – 10 code I 20 – 25	8	2004 Victoria hospital
	48	2004 St Jude Hospital
Cerebrovascular disease ICD – 10 code I 60 – 69	60	2004 St Jude Hospital

Health service utilization data

The availability of health service utilization data is shown in Table 4. Annual outpatient visit costs for the public sector were unavailable for most countries. Private sector data for the same visits were unavailable in all countries. This com-

Table 4: Summary of health service utilization data availability from seven CARICOM member countries

Health service utilization data		Country						
		Antigua and Barbuda	Bahamas	Barbados	Guyana	Jamaica	St Lucia	Trinidad
Annual outpatient visit costs[a]								
Public	– Diabetes	N/A[b]	✔[c]	N/A[b]	N/A[b]	✔[c]	N/A[b]	N/A[b]
	– Hypertension	N/A[b]	✔[c]	N/A[b]	N/A[b]	✔[c]	N/A[b]	N/A[b]
Private	– Diabetes	N/A[b]	N/A[b]	N/A[b]	N/A[b]	N/A[b]	N/A[b]	N/A[b]
	– Hypertension	N/A[b]	N/A[b]	N/A[b]	N/A[b]	N/A[b]	N/A[b]	N/A[b]
Annual renal dialysis costs[d]								
Haemodialysis – public		✔[c]	✔[c]	✔[c]	N/O[e]	✔[c]	✔[c]	N/A[b]
Haemodialysis – private		N/O[e]	✔[c]	✔[c]	N/O[e]	✔[c]	✔[c]	N/A[b]
Peritoneal dialysis – public		N/O[e]	✔[c]	✔[c]	N/O[e]	✔[c]	N/O[e]	N/A[b]
Peritoneal dialysis – private		N/O[e]	✔[c]	N/O[e]	N/O[e]	N/O[e]	N/O[e]	N/A[b]
Annual hospital costs								
Diabetes discharges		✔[c]	✔[c]	✔[c]	✔[c]	✔[c]	✔[c]	N/A[b]
Diabetes-related amputations		N/A[b]	N/A[b]	✔[c]	✔[c]	✔[c]	✔[c]	N/A[b]
Hypertension discharges		✔[c]	✔[c]	✔[c]	✔[c]	✔[c]	✔[c]	N/A[b]
Investigative procedures		✔[c]	✔[c]	✔[c]	✔[c]	✔[c]	N/A[b]	N/A[b]

[a] Refers to consultation costs
[b] N/A – Not available
[c] ✔ Available
[d] Aggregated data for all underlying diagnoses
[e] N/O – Not offered

ponent comprised unit costs for consultations and number of visits made in a specified year. In Antigua and Barbuda, Barbados, Guyana and Trinidad and Tobago, healthcare is provided free of cost to the patient in the public health system and none of the persons interviewed had any idea of the real cost of the consultations. In Bahamas, children, persons 65 years and over, civil servants and persons deemed indigent are exempt from fee payment in the public sector and so the data received did not include the consultation costs for these persons. For St Lucia, the data obtained were only for the number of new cases documented in the national diabetes and hypertension register which was introduced in 2002. Information received was that the data quality was poor due to incomplete or absent reporting from many of the country's health centres.

An attempt was made to estimate the relative contribution of annual renal dialysis costs attributable to either diabetes or hypertension. However, the data obtained were not disaggregated by underlying cause and are thus excluded from Table 4.

Annual hospital costs in the public sector and costs of investigative procedures in both public and private sectors were readily available for almost all countries. The notable exception was Trinidad and Tobago where this information was unavailable from the Ministry of Health during the period of the study. This was due to problems with the flow of information from the regional to the national level.

Health information systems

There was no standardized regional surveillance system in place for diabetes, hypertension, their complications and risk factors in the countries visited. However *ad hoc* data collection systems such as special surveys provided information not routinely collected. As mentioned previously, the prevalence data for Bahamas, Barbados and Jamaica were obtained from such studies.

Computerized systems were in place at the national level in all the countries visited, however the ability of records staff to retrieve data on specific diagnoses was limited in Trinidad and Tobago and Guyana. With the exception of Jamaica and Bahamas, the records office within main public hospitals in all other countries either had no computers or inadequate numbers. For some, the capacity and efficiency of the computers were below optimal levels. The status of computerized data collection systems within health centres was not ascertained as the focus was to obtain morbidity data according to ICD-10 coded diagnoses which are only available from hospitals throughout the English-speaking Caribbean.

At the national level, mortality data for the NCDs were collected and collated by a centre/department responsible for vital registration which operated as a separate entity and/or

fell within the domain of the Ministry of Health. The summarized data was then sent to CAREC, the submission for a particular year being due 18 months later. Inconsistencies in reported data were identified. Table 5 illustrates this point. The crude death rates obtained from CAREC for Guyana

Table 5: Crude death rates per 100 000 population for four selected CARICOM countries

Crude death rates per 100 000 population				
Country (year)	**Diabetes Mellitus**		**Hypertension**	
	PAHO[a]	**CAREC[b]**	**PAHO[a]**	**CAREC[b]**
Bahamas (2000)	34.8	34.6	35.5	35.2
Barbados (2000)	84.9	84.1	48.5	48.0
Guyana (2000)	29.8	100.8	27.5	64.0
Trinidad (1999)	102.0	96.7	27.2	31.3

[a] PAHO Health Statistics from the Americas. 2006 Edition Chapter IV. Deaths and estimated rates per 100 000 population by age group and sex, and male: female ratio, for cause groups of the PAHO 6/67 List (ICD-10) by country and year

[b] CAREC Epidemiology Division October 2005

were over three times greater for diabetes and more than twice that for hypertension when compared with the data from PAHO. Possible reasons for the inconsistencies are simultaneous reporting. The PAHO retrieves mortality data independent of CAREC. We are unclear of processes used to clear inconsistencies. Additionally, it is not unusual for PAHO to compute estimates if data are unavailable from a particular country.

Other issues related to accuracy and completeness of reporting also arose. These included the perennial problem of doctors not providing sufficient information or inaccurately completing case summaries and death certificates. In most instances, there were inadequate numbers of health records and statistical personnel dedicated to the tedious task of collecting, collating and analyzing data.

All countries visited had a system of routine collection of morbidity data on chronic diseases such as diabetes and hypertension within the public health system. (None was identified for the private sector.) These data were collected at various primary healthcare facilities and hospital inpatient and outpatient departments. As stated previously, the coded diagnoses were only available from public hospital case summaries for discharges which are completed by medical doctors only. This is standard practice throughout the English-speaking Caribbean. Monthly summaries were then submitted to an intermediate level, for example, a parish or regional health authority and then finally to a designated health information unit within the respective Ministry of Health. Each country had a statistician at the level of the Ministry of Health.

As was the case with the mortality data, although these systems existed, in some instances the data were unreliable because of deficiencies related to incomplete or inaccurate records. Additionally, other challenges related to the accuracy of coding practices were unearthed. For example, in some countries, most of the cases of diabetes discharges were coded as unspecified diabetes, ICD-10 code E14 which should exclude insulin-dependent diabetes and non-insulin dependent diabetes (31). It is common knowledge that the majority of persons discharged from hospital for diabetes would have received treatment with insulin and/or oral hypoglycaemic agents. This dilemma for the coding staff often arose in two situations: 1) cases where physicians documented diagnoses according to the newer classification of diabetes mellitus to either Type I and Type II *versus* the older nomenclature of insulin-dependent diabetes mellitus and non-insulin dependent diabetes mellitus (35) which was more compatible with the ICD-10 coding system and 2) physicians failed to classify the type of diabetes anywhere in the case notes or summary.

This study did not explore the level of analysis and subsequent use of the information generated to support decision-making.

DISCUSSION

This study was undertaken to expand the analysis of the costs attributable to diabetes and hypertension, and also to determine the adequacy of the information systems to provide data readily. The development of policies that will address the underlying risk factors of the cardiovascular diseases will require the retrieval of sound data to conduct the economic and other analyses in order to provide high quality information to support decision-making.

Whilst it is commendable that all countries had in place some system of collection of data for both diabetes and hypertension, a number of problems commonly encountered in routine health information systems (36) were identified. Of special concern were those deficiencies identified with the reliability and validity of the data received. Firstly, the data elements collected were not standardized across all countries at all levels. Additionally, data from multiple years, sources and with varying degrees of completeness and accuracy were obtained which limited the ability to make meaningful comparisons across the region. It was also evident that there was under-reporting and/or inaccuracies in the data obtained. For example, Table 2a illustrates this point for Bahamas, Guyana and St Lucia where disease specific mortality rates for diabetes mellitus far exceeded the morbidity rates which combine total discharges inclusive of those due to death. This is implausible despite the variations in the reporting years for the mortality and morbidity data. As mentioned previously, health records staff revealed that most of the cases of diabetes were being coded as unspecified diabetes E14.0 although this code should exclude insulin-dependent [E10] and non-insulin-dependent diabetes [E11] (31).

Secondly, an attempt was made to collect data to faci-

litate the analysis of cost-specific complications related to both diabetes and hypertension, such as ischaemic heart disease, cerebrovascular disease, chronic renal failure, hypertensive and diabetic retinopathy and peripheral circulatory complications (including amputations). With the exception of cerebrovascular disease, these are disease conditions for which there are universally accepted intermediate biological and clinical markers which signal the need for implementation of interventions at one or more levels of prevention (namely primary, secondary or tertiary). Of particular concern was the inability to ascertain the unit costs for a number of services in those countries that provided care free of cost to patients within the public sector. Without this baseline information, it becomes virtually impossible to monitor and/or evaluate the cost-effectiveness and efficiency of programmes. On one hand, it could be argued that the cost-burden analysis was limited by the quality and unavailability of data. However proponents of the 'action-led' approach to reforming health information systems (which focusses on how information generated will influence decisions for the health of a population) argue that frequent use of data would rapidly detect anomalies and errors received and so the poor data quality is more a consequence of rather than cause of its underutilization (37). This underutilization of data is perhaps one major reason for the dearth of information available on healthcare costs attributable to hypertension and diabetes within the region. It must be noted that other studies were identified which attempted to measure the economic burden of diabetes in the Caribbean (38, 39). The data used were not primary data but, in each case, analysis was derived using extrapolations of prevalence estimates (40, 41).

Thirdly, the data management systems in hospitals were not linked to facilitate inter-operability. This inter-operability is critical to ensuring, for example, that epidemiological and health service utilization data can be integrated to generate cost-effectiveness estimates and other information required to compare options for health investment (29).

Much of this report has highlighted issues related to the retrieval of epidemiological and health service utilization data collected on diabetes, hypertension and specific related complications for the purpose of performing specific economic cost analyses. The further management, analysis, dissemination and ultimate use of this health information in the respective countries was not fully explored. However, it is disconcerting that in some countries reliable information was not available at the national level, which begs the question as to the level of evidence-based decision-making employed by policy makers, donor and international agencies concerned with health.

For sometime now, the CARICOM member states have recognized the importance of a well-organized HIS for identifying priority areas for action as well as monitoring and evaluating progress toward subregional, regional and global health goals. Indeed, this was one of the specific indicators that was to be accomplished by 1993 under the Caribbean Cooperation in Health Initiative approved by the CARICOM Heads of Government in 1986 (42). Since then, attempts have been made to develop/strengthen HIS within the Caribbean. Notable examples include projects such as the 'Barbados and the Eastern Caribbean Countries Management Information Systems for Community Health Services' initiated in 1992 (43) and more lately, a four-year project dubbed 'Human Resources Training and Development in Health Information Systems for the English-speaking Caribbean which successfully ended in 2001 and benefitted 14 countries (44). CAREC continues its efforts to upgrade the regional and national mortality databases. Results of a survey conducted among its member countries indicated that inputs from physicians limit the quality of data; although training for mortality coders has been consistently provided about 78% have never been evaluated and there was need for regular evaluation and audit of mortality surveillance and vital registration systems (45).

In conclusion, this study has highlighted deficiencies in the quality and availability of health information to facilitate cost-burden analysis of diabetes and hypertension and related complications in the Caribbean. It must be stressed that this report does not attempt to quantify or analyze the magnitude of the problem of hypertension, diabetes and the related complications in the Caribbean. While the time available for collection was short, the data requested are such that they should be readily available, which was not the case. It is possible that further intensive local work would have provided all the data needed, but a functional HIS should be able to provide critical data readily.

A considerable amount of work will have to be done to correct the deficiencies observed. For example, training of staff must be ongoing and not confined to one set or level of staff, for example coders, but include physicians and other persons at all levels within the health system, from the peripheral to the national and be inclusive of all relevant categories of health and health related staff. Basic equipment is necessary in many countries.

Standardization of at least the data elements, procedure for collection, collation and analysis of the data must also be done. There should be two approaches to that collection of such data. First there should be the regular system for collecting basic mortality and morbidity data. In addition, some of these should be amplified by periodic surveys. Periodic community surveys are expensive and the health sector authorities must explore the possibility of including health elements in the routine data collection that is done, as for example in the Jamaica Survey of Living Conditions (46). These periodic surveys provide data on, items such as lifestyle behaviour and household health expenditure which often help to explain health outcomes.

Establishment of accurate, agile health information systems will be a critical prerequisite to any major effort to control the cardiovascular diseases and diabetes mellitus in the Caribbean. If the reduction of morbidity and mortality

from cardiovascular diseases and diabetes mellitus is to remain a goal of the CARICOM governments, it is imperative that the HIS design be aligned with this priority area of focus in order that it can deliver the information that researchers and policymakers need in a timely manner. At this stage of the epidemiological transition, economic evaluations such as cost of illness studies and cost-effectiveness analyses will need to be undertaken more frequently to provide valuable information for decision-making by policy makers. The CARICOM governments must therefore commit themselves to mobilizing and sustaining the resources (human, material and financial) that are necessary.

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