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Population-Based Surveillance for Cardiovascular Disease in the Caribbean: Challenges and Opportunities for Regional Approaches

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Abstract

Purpose of Review—Non-communicable diseases (NCDs), including cardiovascular disease (CVD), are the leading causes of morbidity and mortality in the Caribbean. In response to this growing epidemic, regional and global organizations mandated the collection of real-time and accurate population health data to address surveillance health data gaps. The purpose of this review was to assess surveillance activities implemented in the Caribbean region from 2006 to 2016 and the availability of widely disseminated CVD surveillance data.

Recent Findings—A review of surveillance activities in the region in 2011 showed modest progress in compliance with NCD-related mandates. Our study found that few (12%) countries implemented surveillance surveys yearly and 39% implemented surveys two or more times during 2006–2016. Sixty-four percent of countries included in our review collected data on the six recommended CVD risk factors.

Summary—Future efforts to generate consistent and timely surveillance data may require collaborative approaches to implement, interpret, and translate surveillance data.

Keywords

Caribbean; Non-communicable disease; Cardiovascular disease; Surveillance

Introduction

Non-communicable diseases (NCDs), mainly cardiovascular disease, cancer, chronic respiratory disease, and diabetes, have replaced infectious disease as the leading causes of mortality across the world [1]. Approximately 35 million people die each year from these NCDs, accounting for more than 60% of all deaths globally, and three-quarters of those

Compliance with Ethical Standards

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deaths occur in low and middle income countries (LMIC) [1]. Concerns for this global health threat are reinforced by estimates from the World Health Organization (WHO) that total deaths from NCDs will further increase by 17% over the next 10 years [2].

The Caribbean region has played a lead role in highlighting the need for an urgent and unified response to the emerging global NCD pandemic. The 2001 Nassau Conference in the Bahamas called for a regional response to controlling and preventing NCDs and established the Caribbean Commission on Health and Development [3•]. A subsequent 2002 mandate from the scientific council of the Caribbean Epidemiology Centre (CAREC) required the implementation of NCD surveillance systems to collect data on disease and associated risk factor prevalence. This mandate was reaffirmed in the 2006 Pan-American Health Organization (PAHO) and Caribbean Community Secretariat (CARICOM) jointly led report on health and development. Both the 2002 and 2006 reports called for improvements in health information system infrastructure, measurement, and data collection [4•]. CARICOM delegates ultimately initiated a process resulting in the first high-level United Nations (UN) meeting on NCDs in 2011. This was only the second UN convening in its history to focus on a health topic, the first being the 2001 meeting on the global HIV/AIDS crisis [5]. The UN NCD meeting emphasized the disproportionate burden faced by small countries and revealed limitations in the ability to address this global pandemic in the absence of data from limited resource settings.

Despite the consensus on the critical importance of real-time and accurate population-level NCD health data to inform public policy and strengthen healthcare systems, the extent to which small countries and territories have conducted surveillance activities to collect this data since regional mandates and the UN meeting has not been comprehensively reviewed. We focus this review on the state of publicly available population health NCD data in the Caribbean. We highlight the Caribbean because of the region's central role in the global conversation on NCDs and its recognized commitment to making advances in this arena. Given these reasons, we postulate that the state of available population-level NCD data in this region likely represents the best case scenario for what small countries might achieve in the context of limited resources. The main objective of this paper is to present a comprehensive assessment of the region's efforts to establish and implement surveillance for cardiovascular disease (CVD) risk factors and outcomes since the 2006 report. We expand on previous work done in this area [6•, 7] by capturing surveillance efforts for a broader definition of the Caribbean region and by documenting types and frequency of surveillance over the 10-year period. Finally, we address possible barriers to ongoing NCD surveillance efforts within the Caribbean region.

Methods

Inclusion Criteria for Caribbean Countries

We examined the availability of CVD surveillance data during 2006–2016, following the 2002 CAREC mandate and 2006 PAHO and CARICOM reports calling for increased surveillance in the region. We included Caribbean countries and territories that are full or associate members of CARICOM and non-member countries and territories that lie in the Caribbean Sea. This expanded definition of the Caribbean region includes countries located

in the Greater and Lesser Antilles of the Caribbean as well as non-English-speaking islands. The countries included in this review have diverse populations but share similar cultural contextual factors and system-level challenges associated with addressing NCDs.

We grouped countries according to sovereignty, dependent territorial status, or fully integrated territorial status. These groupings reflect important differences in resources, capacity, and priorities that influence the availability of health data in the region. In total, we examined the surveillance data for 33 Caribbean countries and territories. Table 1 lists the countries included in each category. We identified publicly available NCD data sources, assessed the collection of CVD risk factors and outcomes, and determined the frequency of data collection and methods employed to assess the availability of data to provide cardiovascular surveillance in the region.

Identification of Publically Available Population CVD Data

We reviewed published literature and other publicly available information on public health data sources in the Caribbean to determine the availability of prevalence and incidence data for CVD and associated risk factors. The data sources highlighted in this paper were identified from manuscripts, reports, and data presented online. We conducted searches using PubMed, Google, Google Scholar, and global and regional chronic disease databases to identify sources of CVD risk factor prevalence, incidence, and mortality data for the Caribbean. We combined the following search terms to identify articles containing these data: “Medical Records,” “public surveillance,” “non-communicable diseases,” “monitoring,” “burden of disease database,” “cause of death,” “mortality rates,” “epidemiology center,” “global youth tobacco survey,” “stepwise survey,” “national disease registry,” “surveillance system,” or any combination of these terms AND “Caribbean,” “small island,” “developing states,” “PAHO,” “WHO,” “CAREC,” “CARICOM,” or any combination of these terms and “hypertension,” “diabetes,” “nutrition,” “physical activity,” “obesity,” “Health survey,” “vital statistics,” “cardiovascular disease,” “CVD,” “non-communicable disease,” “NCD,” and “risk factors”. We identified and reviewed additional sources from our initial search. Finally, the search strings were combined with the names of the Caribbean countries and territories included in our review. Internet searches were also conducted via Google using the same search terms to identify publicly available sources of data not contained in the peer-reviewed literature. We searched the websites of global and regional organizations that conduct work in the Caribbean to obtain information on surveillance activities within each country and the region. In addition, the websites of country Ministries of Health and government websites were reviewed to identify available CVD surveillance data.

Data sources were reviewed to determine the capture of minimum indicator variables for chronic disease surveillance as recommended by PAHO [8]. These indicators include relevant CVD risk factors such as hypertension, diabetes, obesity, smoking, physical activity, and nutrition. We also determined how many studies captured CVD incidence and mortality.

Data Sources, Method of Collection, and Assessment Interval

We identified data that was systematically collected and categorized as follows: (1) national, (2) population-specific, or (3) hospital or record based. Examples include national health surveys, school-based surveys, death records, and healthcare data infrastructures. We also identified commonly used methods to collect these data: self-report, record abstraction, clinical assessment, or administrative data. Finally, we assessed the frequency of data collection efforts in the region in order to evaluate surveillance capability and effectiveness.

Results

The sections that follow summarize the characteristics of surveillance activities in the Caribbean region. Figure 1 presents the most frequently used surveillance surveys among the countries and territories included in our review. We also describe the availability of data on specific risk factors associated with CVD.

Data Sources and Risk Factors Assessed

Our search identified several standardized surveys that are used for NCD surveillance in the Caribbean region that included CVD risk factor data. The surveys identified were developed by regional and national organizations with the goal of obtaining data that permit cross-country comparisons. Population-based surveys included the World Health Organization (WHO) STEPwise Approach to Surveillance survey (STEPS), United States Agency for International Development (USAID) Demographic and Health Survey, Caribbean Development Bank Poverty Assessment and Survey of Living Conditions, and the Eastern Caribbean Health Outcomes Research Network (ECHOHN) Health Survey. Other surveys included the Global School-Based Health Survey (GSHS), Global Youth Tobacco Survey (GYTS), both population-specific surveys, and the PAHO/WHO Regional Mortality Database, a registry-based data source. These surveys employed different methodologies; however, each comprised standardized measures that permit country and regional CVD surveillance. Regional organizations such as the Caribbean Public Health Association (CARPHA) recommended the use of the WHO STEPS, also referred to as PAHO/WHO STEPS in the Caribbean, and other regional risk factor surveillance surveys in the region. The WHO STEPS is a multistage standardized survey for collecting, analyzing, and disseminating data on non-communicable disease risk factors for surveillance. This survey is an effort by the WHO to build and strengthen capacity in the region.

During the period 2006–2016, 91% (30/33) of countries and territories included in our search utilized at least one of the standardized NCD surveillance surveys identified or participated in passive surveillance efforts. The PAHO/WHO Mortality Database was the most utilized source of surveillance in the region, with 91% (30/33) of countries participating in this passive surveillance effort. The database functions as a regional mortality information system that passively collects data on deaths registered in country and territory vital registration systems. The WHO STEPS, utilized by 42% (14/33) of countries included in our search, was the second most utilized surveillance survey in the region that provided data on CVD risk factors. Results showed that 79% (26/33) of countries and territories conducted population-based cross-sectional surveillance activities to support

regional surveillance (excluding participation in the PAHO/WHO mortality database) within 6 years following the PAHO/CARICOM report (2006 to 2011), while 9% (3/33) of countries and territories implemented surveys between 2012 and 2016. The ECHORN Cohort Study, which began in 2011, was the only source of cohort data identified that provided data for CVD surveillance within and across countries in the region. The ECHORN cohort is followed prospectively to obtain data on chronic disease risk factors and to ascertain chronic disease outcomes by conducting surveys and clinical assessments every 2 years. Data collection for the first round follow-up data collection is currently underway.

Other surveys implemented in the region specifically targeted youth and focused primarily on tobacco, nutrition, and physical activity. The WHO School-Based Student Health Survey was conducted by 20 of the countries and territories included, while the Global Youth Tobacco Survey was used by 11. The former survey focuses on ten key areas to assess health behaviors and protective factors among youth 13–17 years of age, including tobacco use and nutrition, while the latter focuses specifically on tobacco usage, perceptions, tobacco exposure, and marketing influences among youth 13–15. Less frequently used surveillance initiatives included the USAID Demographic and Health Survey [9, 10], which was only used by Haiti and the Dominican Republic to collect nationally representative health data and the Caribbean Development Bank Country Poverty Assessment and Survey of Living Conditions, used by Saint Lucia, Dominica, Anguilla, and Saint Vincent and the Grenadines. Overall, PAHO/WHO surveys were the most utilized for CVD risk factor surveillance in the region.

In addition to using regional and cross-country standardized surveys, many countries also conducted their own national surveys to assess risk factor prevalence. Aruba, Belize, Barbados, Bermuda, Bahamas, Jamaica, Suriname, Cayman Islands, Cuba, the Dominican Republic, Grenada, Haiti, Suriname, Netherlands Antilles, Puerto Rico, US Virgin Islands, and Curacao all fell within this category. Our findings showed that among smaller countries, data availability was highly variable with some countries having no available risk factor or outcomes data. In addition to biomedical and behavioral risk factors, many of the surveys used in the region also collected data on sociodemographic characteristics associated with CVD including age, race, sex, education, and income. Approximately 64% (21/33) of the countries included in our review collected data on the CVD risk factors examined in our search (i.e., hypertension, diabetes, nutrition, smoking, obesity, and physical activity), while 50% (7/14) of the remaining countries and territories collected data on at least four of those risk factors.

Comparison of surveillance efforts between independent/sovereign countries and dependent territories showed important similarities and differences within and across categories. The majority of independent Caribbean countries used WHO STEPS and, in some cases, national surveillance efforts to assess specific risk factors. Meanwhile, surveillance data for dependent countries and territories came from a variety of sources including existing national surveys developed specifically for dependent countries or territories and in few cases, the WHO STEPS. The British territories, for example, utilized WHO STEPS to obtain CVD risk factor data while the Netherland territories used country specific surveys or had no surveillance data for the selected CVD risk factors. The US territories used national surveys

from the US mainland, including the National Health Interview Survey and Behavioral Risk Factor Surveillance Surveys, to obtain risk factor data annually.

Frequency of Administration of Surveillance Surveys

Our search showed that 13/33 countries and territories conducted surveys two or more times during the 10-year time period. Of the 13 countries, six (Bahamas, Dominican Republic, Haiti, Suriname, Jamaica, and Suriname) implemented regional and country- or territory-level surveillance surveys during this period. For some countries and territories, we could not find surveillance data that were collected within the past 5 years. Findings showed that 16 of 33 countries conducted one or more surveillance activities within the last 5 years. None of the countries and territories included in our search conducted surveillance surveys yearly as recommended, with the exception of Puerto Rico, US Virgin Islands, Jamaica, and Haiti. These findings exclude participation in the PAHO/WHO Mortality Database, in which 18 of 33 countries and territories participated on an annual basis.

Availability of Data to Assess Cardiovascular Outcomes

The results of our search showed that none of the countries included in our review had routine data infrastructures or sources that permitted measurement of incident cardiovascular outcomes during the study time period; however, in a few countries, cohort studies were conducted that permit estimation of incident cardiovascular disease. Examples include a prospective study in the US Virgin Islands that examined factors associated with the development of metabolic syndrome among Caribbean-born persons [11]. The Puerto Rico Heart Health Program, a prospective study of lifestyle, environmental, and biological factors associated with cardiovascular disease, ended in 1980. The Eastern Caribbean Health Outcomes Research Network (ECHORN) Cohort Study is a more recent and currently ongoing initiative (2011–present) that aims to estimate the prevalence and incidence of NCDs including heart disease and stroke.

Many countries participated in the WHO/PAHO Mortality Database increasing the availability of CVD mortality data in the region. The availability of these data permits the estimation of regional mortality estimates from CVD for surveillance purposes and to estimate disease burden. CVD mortality data are available by age and sex groups in the database. Though there are questions regarding the accuracy of death certificate data which are used to generate mortality estimates, it nonetheless serves as a vital source of regional surveillance for CVD burden.

Discussion

Cardiovascular disease (CVD) is the leading cause of morbidity and mortality in the Caribbean and among populations of its diaspora [1, 2], making its reduction a top priority for the Caribbean region. In 2007, the CARICOM summit on NCDs issued 27 concrete and discrete commitments to controlling NCDs, including CVD, in the region. One of these commitments was the urgent establishment of platforms necessary for research and surveillance of NCD risk factors [3•, 4•, 5]. An assessment of the Caribbean's adherence to these 27 CARICOM summit commitments by the Healthy Caribbean Coalition in 2010

demonstrates modest and very mixed response across the region, with countries such as Barbados, Trinidad and Tobago, and Bermuda being the most adherent to the guidelines, and countries such as Anguilla, Haiti, and Saint Vincent and the Grenadines being among the least adherent [6•, 7, 8, 12•, 13]. Our more specific assessment of the region's commitment to surveillance efforts since the 2006 PAHO/CARICOM Report and adoption of the WHO STEPS methodology for risk factor surveillance demonstrates a modest but mixed response across the region. Countries such as Jamaica, Haiti, US Virgin Islands, and Puerto Rico were the only ones to (1) conduct surveillance activities within 6 years of the PAHO/CARICOM report, (2) implement national/territory-wide surveillance activities, and (3) conduct surveillance activities annually. Meanwhile, smaller countries and territories such as Turks and Caicos, Curacao, Martinique, and Montserrat had more narrow surveillance efforts, either limited to population subgroups or conducted through passive efforts (e.g., PAHO/WHO Mortality Database). This mixed implementation of surveillance activities across the region results in variable prevalence and risk factor data for CVD and limits the region's ability to accurately determine prevalence and trends for CVD, develop appropriate interventions to reduce mortality rates, and conduct economic analyses [14] to inform healthcare financing and ensure greater access to basic health technologies and essential medicines.

Findings from our review demonstrate that despite the launch of initiatives such as the Collaborative Action for Risk Factor Prevention and Effective Management of NCD (CARMEN) network—a network of the Ministries of Health of the Americas that aims to reduce risk factors for NCDs through health policy, advocacy, health promotion, and disease prevention, surveillance, and integrated management [6•]—and implementation of the WHO STEPwise survey across the region over the last 15 years, there is still room for improvement. Specifically, we identified the following four areas in which surveillance systems at the local and regional level could be strengthened: (1) timeliness of surveillance information, (2) standardization of measurement approaches to enhance regional opportunities for collaboration and strategic planning, (3) ability to accurately predict CVD risk patterns from surveillance information, and (4) capacity to integrate and interpret data into products for dissemination to relevant stakeholders.

In the case of timeliness, we posit that infrequency in surveillance activities diminishes a country's ability to adequately monitor changes in risk factor prevalence and runs the risk of outdated information being used to inform practice, policy, and strategic planning. The long-term consequence of using outdated information is a widening health gap because contemporary risk factors would neither be captured nor taken into consideration. Timely data collection would enhance opportunities for regional collaboration and strategic planning to address increasing prevalence of chronic diseases in the region.

As a further limitation to the utility of the surveillance data being collected, our assessment showed that only 58% of the countries and territories in our review collected all the recommended CVD risk indicators. The lack of standardization in variables included on surveys leads to gaps in information for CVD indicators by country and sub-regions and hampers the ability to have cross-country discussions and comparisons or to make the case for additional resources to combat this pandemic. A move towards consistent collection of

the minimum set of indicators across countries as well as standardizing times for implementation of these surveillance efforts would support PAHO/WHO goals to establish a regional chronic disease surveillance database that contains complete and consistent data [15]. Countries should also consider updating the list of indicators to incorporate emerging risk indicators such as sleep patterns, sexual orientation, and healthcare access and utilization to advance understanding of social determinants and group differences associated with CVD in the region.

From our assessment, we observe that the majority of surveillance surveys implemented are cross-sectional. This explains the paucity of incidence and case fatality data available for the region—data necessary for the accurate estimation of CVD burden. This pattern of implementing cross-sectional surveys in the region was highlighted more than a decade earlier in a review of hypertension prevalence studies in Latin America and the Caribbean (LAC) and suggests that factors such as time, financial resources, and capacity may play into the decision to opt against launching prospective studies. As a consequence, the region has little information about the causal pathways and temporal changes in both risk and protective factors and outcomes specific to the region for CVD.

Point four highlights the challenges to integration, interpretation, and dissemination of CVD data in the region. The first challenge to data integration across the region is the irregular implementation of surveillance efforts in many countries. This irregularity may be a result of limited funding and resources with which to implement data collection as recommended. Using publicly available data from one funder, the National Institutes of Health (NIH), we found that 17 research projects with a focus on CVD in the Caribbean were funded between 2006 and 2016. Fourteen out of those 17 projects were awarded to the US territories. The majority of these funded research projects spanned several years, and at least three established a research and clinical infrastructure within the region. Raising the priority of funding for NCD research within the region from both public and private sectors will help boost scientific output from the region [16, 17]. Additional barriers to the routine implementation of existing NCD surveillance systems include competing government priorities, limited resources, and economic instability. In response to this challenge, agencies such as the NIH and CARPHA have hosted training workshops to increase awareness of available grant funding sources and increase capacity in research methodologies relevant to CVD study [18]. Similarly, organizations in the UK such as the Medical Research Council (MRC) and Wellcome Trust and Canada's International Development Research Centre have expanded health research capacity-strengthening funding opportunities to include NCD research or have funded NCD research with capacity-strengthening elements.

To increase integration and information exchange in the region around CVD, the next generation of surveillance initiatives should emphasize collaborative approaches to data collection and support greater translation of collected information into practice and policy. A collaborative approach to surveillance would allow for the pooling of resources, expertise, and knowledge needed to facilitate a scale-up of activities, particularly in the smaller countries and territories. It would support continuous data collection and reporting, cross-country comparisons, information sharing, and the generation of interventions with regional applicability. Further, these collaborative approaches may improve the accuracy, timeliness,

and comparability of surveillance information. The African-Caribbean Cancer Consortium (AC3) and ECHORN, which work across several countries and territories in the Caribbean, and CARPHA are examples of research and public health collaborations, respectively, that aim to expand and strengthen human resource capacity, increase information exchange and partnerships around NCDs prevention and control, strengthen surveillance, and support additional research efforts in the Caribbean region.

Dissemination of surveillance data is equally important to the region's efforts to document and address CVD outcomes and risk factors. The fact that publicly available prevalence and incidence data for CVD outcomes are still scant despite the launch of surveillance activities in several countries and territories within the region suggests the need for more attention and better strategies to disseminate data. Scoping reviews of literature emerging from LAC shows that while articles on CVD have increased between 2001 and 2010, the scientific output does not reflect the magnitude and extent of the NCD epidemic in the region [19]. Further, larger Caribbean countries such as Cuba and Jamaica continue to produce the highest number of articles [20]. An assessment of the progress of LAC in implementing actions to address NCDs revealed only five Caribbean countries and territories had a national reporting system and annual reports that included indicators of NCD and risk factors [6•]. Research initiatives such as the United States of America Caribbean Alliance for Health Disparities Research (USCADHR) are working to improve the visibility of NCD research in the Caribbean and/or with Caribbean populations through the expansion of an e-platform that collates and disseminates NCD research. However, greater strides must be taken to disseminate accurate, timely, and comparable regional statistics that are essential for the development of evidence-based practice and policies.

In the face of limited resources, the region will need to think creatively about the ways it harnesses the many assets already in existence. One such asset is the various stakeholders with shared interest and commitment to addressing CVD in the region. Engaged and activated stakeholders such as the Healthy Caribbean Coalition, the Heart and Stroke Foundations of Barbados Incorporated, Guyana Chest Society, and others should be leveraged. These groups will be integral to the spread and uptake of surveillance data across multiple audiences, to the efforts to improve and sustain local capacity, and to ensuring accountability among policy and community leaders. In addition, finding alternative ways to use relatively inexpensive methods, such as mobile devices, to capture surveillance data may improve the timeliness and relevance of the CVD data being collected.

There are few notable limitations to this review. First, our search was confined to publicly available data. The countries and territories included in our review may conduct surveillance activities for which data are not made publicly available. It is also possible that limited resources may have precluded the dissemination of surveillance activities in some countries and territories. The findings presented here, may therefore underestimate regional surveillance activities. However, our goal was to assess the availability of widely disseminated surveys and other tools that are critical to CVD surveillance efforts in the Caribbean. Second, the surveillance activities of Caribbean countries that did not meet the inclusion criteria for this review remain unknown. Data from these countries could impact the overall findings from our review. Nonetheless, our review captures a large number of

countries and territories in the region, provides a useful assessment of surveillance efforts, and highlights key implementation challenges. Third, we did not review costs associated with the different surveillance efforts. Future work should aim to identify sustainable sources of funding to support routine surveillance efforts, best practices for cost-effective implementation, and targeted areas for improvement.

Conclusion

In summary, the Caribbean region has been a leader in the field of NCDs by first calling attention to the undue NCD burden faced by its population and then taking action through the implementation of surveillance activities. In the years following the CAREC mandate, the region has made remarkable progress in collecting information on CVD. Findings from our review makes the case that the region's efforts could be refined further to enhance the utility of the data being collected and better leveraged for strategic planning on a regional level as well as to garner additional funding. Meeting the WHO adopted target of reducing premature mortality from NCDs by 25% between 2012 and 2025 [21] will require more concerted and creative regional efforts to invest in surveillance activities as a starting point to benchmark progress towards these goals. The process of achieving target goals will not only improve CVD outcomes but also provide best practices that will help to address CVD burden in the region.

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Fig. 1.
Common sources of surveillance data (for CVD) in the Caribbean and frequency of implementation

Table 1

Caribbean countries and territories included in review of available data for CVD surveillance

Independent countries	Antigua and Barbuda, Bahamas, Barbados, Belize, Bermuda, Cuba, Dominica, the Dominican Republic, Grenada, Guyana, Jamaica, Haiti, Saint Lucia, Saint Vincent and the Grenadines, Suriname, Saint Kitts and Nevis, Trinidad and Tobago
Dependent countries and territories	Anguilla, Aruba, Bonaire, British Virgin Islands, Cayman Islands, Curacao, Martinique, Montserrat, Puerto Rico, Saba, Saint Barthelemy, Saint Martin, Sint Eustatius, Sint Maarten, Turks and Caicos, US Virgin Islands