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## Advancing Cancer Control Through Research and Cancer Registry Collaborations in the Caribbean

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### Abstract

**Background**—Few national registries exist in the Caribbean, resulting in limited cancer statistics being available for the region. Therefore, estimates are frequently based on the extrapolation of mortality data submitted to the World Health Organization. Thus, regional cancer

surveillance and research need promoting, and their synergy must be strengthened. However, differences between countries outweigh similarities, hampering registration and availability of data.

**Methods**—The African-Caribbean Cancer Consortium (AC3) is a broad-based resource for education, training, and research on all aspects of cancer in populations of African descent. The AC3 focuses on capacity building in cancer registration in the Caribbean through special topics, training sessions, and biannual meetings. We review the results from selected AC3 workshops, including an inventory of established cancer registries in the Caribbean region, current cancer surveillance statistics, and a review of data quality. We then describe the potential for cancer research surveillance activities and the role of policymakers.

**Results**—Twelve of 30 Caribbean nations have cancer registries. Four of these nations provide high-quality incidence data, thus covering 14.4% of the population; therefore, regional estimates are challenging. Existing research and registry collaborations must pave the way and are facilitated by organizations like the AC3.

**Conclusions**—Improved coverage for cancer registrations could help advance health policy through targeted research. Capacity building, resource optimization, collaboration, and communication between cancer surveillance and research teams are key to obtaining robust and complete data in the Caribbean.

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## Introduction

Cancer is increasing in frequency and is a leading cause of death worldwide. As such, it is a principal priority for health authorities of many countries.<sup>1</sup> An estimated 14 million new cancer cases occurred in the world in 2012.<sup>2</sup> Lung, female breast, colorectal, prostate, and stomach cancers accounted for nearly 50% of all cases diagnosed and of cancer-related deaths worldwide.<sup>2</sup> The Caribbean, whose location is detailed in Fig 1, is no exception, with malignant neoplasms being the leading cause of mortality for those living in the Caribbean.<sup>3</sup>

Although Caribbean nations share the same urgency in the fight against cancer in terms of surveillance and research, important limitations exist in addressing this issue.<sup>4,5</sup> For example, although different countries share many similarities in terms of environmental, ethnic predominance (most English-speaking Caribbean countries comprise majority African-origin populations), and other common risk factors, geographical, demographic, and ethnic differences are also present.<sup>6</sup> Not all Caribbean countries are islands, and their populations vary in size: from more than 11 million in Cuba to about 5,000 for Montserrat.<sup>7</sup> Some countries have majority populations of East Indian ethnic origin, and many have an increasing proportion of their population of mixed ethnic background.<sup>8</sup>

Economic differences also exist, with some Caribbean countries classified as high- (eg, Barbados, Bahamas), upper-middle (eg, Jamaica, Suriname), lower-middle (eg, Guyana), or low-income economies (eg, Haiti).<sup>9</sup> Although ethnic and environmental factors influence trends in rates of cancer incidence and mortality, such factors are generally correlated with economic development.<sup>10,11</sup> Variation in economic development throughout the Caribbean also means a range of access to and quality of health care across different countries; in some communities, insufficient or inadequate health insurance, or geographical remoteness, or

estrangement from adequate specialized health infrastructure has resulted in a higher frequency of cancers with poor prognoses (due to diagnosis and treatment at advanced stages) and more deaths.<sup>12</sup>

It is necessary to monitor epidemiological trends in cancer (eg, through surveillance), particularly in low-resource countries undergoing demographic transition with increasingly aging populations like those in the Caribbean.<sup>6,13</sup> This is even more important because high-quality data on cancer are lacking from low- and medium-resource countries, and, considering the differences between countries across the Caribbean, generalizations have been difficult.<sup>10</sup> In addition, research is vital for understanding the specific determinants of most cancers, especially those affecting high-risk populations such as African Caribbean or indigenous populations, such as Amerindians, and to provide better guidance and evaluation of cancer control policies to develop targeted and efficient programs for cancer prevention and care.<sup>6,14,15</sup> Although the distinction between surveillance and research is important, the synergy between them is often overlooked. Surveillance is necessary for continued disease monitoring, and its data analysis may hint at previously unknown insights. By contrast, the value of research lies in the ability of researchers to examine what can only be alluded to, but not proved, using surveillance data. Therefore, surveillance is often termed *hypothesis generating* and research *hypothesis testing*. Collaboration between researchers using these different methods for generating information on a subject can be powerful, although often they run along parallel paths.<sup>16</sup>

However, considering the intra-Caribbean variation, countries in the region cannot be “equal in arms” against the cancer epidemic. Not all Caribbean countries possess sufficient essential health surveillance infrastructure to provide efficient cancer registration and quality cancer data. Where established and efficient cancer surveillance is present, little optimization of cancer registration exists to help make progress through cancer research. In addition, knowledge, resources, and collaboration may be too limited to utilize and address research needs overall, including via cancer registries.<sup>14</sup>

Several prior regional scientific workshops and conferences have identified the few existing cancer surveillance systems of the Caribbean and have highlighted the ongoing scientific collaborations implicating cancer registries.<sup>17–19</sup> These workshops advocate for more dynamic and productive communication between relevant partners while also emphasizing the growing importance of, and need for, cancer registration to address the increasing cancer burden through targeted research.<sup>17–19</sup>

Herein we describe the latest 2013 and 2014 workshops coordinated by the African-Caribbean Cancer Consortium (AC3), which facilitates and promotes the collaboration between cancer research and surveillance. We also join the AC3 and other concerned cancer surveillance and research stakeholders in the Caribbean in calling for the reinforcement of cancer registration in the Caribbean to expand population-based coverage by cancer registries and obtain more complete and reliable data for their strategic use in guiding requisite cancer control interventions and collaborative research.

## Caribbean Nations

The Caribbean region refers to the 15 Caribbean nation members and 5 associate members of the Caribbean Community (CARICOM), in addition to 10 other Caribbean nations (French Martinique, Guadeloupe, and French Guiana, as well as other Caribbean islands of the Greater and Lesser Antilles; see Fig 1).<sup>20</sup> The 30 Caribbean nations referred to in this paper include Anguilla, Antigua and Barbuda, the Bahamas, Barbados, Belize, Bermuda, the British Virgin Islands, the Cayman Islands, Cuba, Dominica, the Dominican Republic, French Guiana, Grenada, Guadeloupe, Guyana, Haiti, Jamaica, Martinique, Montserrat, The Netherlands Antilles (Aruba, Bonaire, Curaçao, Saba, St Eustatius, and the Dutch half of St Martin and St Maarten), Puerto Rico, St Barthélemy, St Kitts and Nevis, St Lucia, St Martin (the French half of St Martin and St Maarten), St Vincent and the Grenadines, Suriname, Trinidad and Tobago, the Turks and Caicos, and the US Virgin Islands. Although they predominantly comprise islands in the Caribbean Sea for which the official language is English, notable exceptions exist. French Guiana, Suriname and Guyana are on mainland South America while Belize is on mainland Central America; French Guiana, Haiti, Martinique, Guadeloupe, Saint Barthélemy and Saint Martin are French-speaking, while the official language of Suriname, Aruba, Bonaire, Curaçao and Sint Maarten is Dutch, and that of Cuba, the Dominican Republic, and Puerto Rico is Spanish.

## African-Caribbean Cancer Consortium

The mission of the AC3 is to study viral, genetic, environmental, and lifestyle factors for cancer risk and outcomes in populations of African descent.<sup>21</sup> The consortium is part of the Epidemiology and Genomics Research Program consortia of the National Cancer Institute (NCI), which is composed of 3 connected networks of investigators in the United States, Africa, and the Caribbean region.<sup>21</sup> The AC3 has 120 members and is a broad-based resource for education, training, and research on the etiology, screening, prevention, treatment, and survivorship related to cancer in populations of African descent.<sup>21</sup> Within the AC3, 7 Caribbean cancer registries are represented (5 are national: Barbados, Guyana, Guadeloupe, Martinique, and Trinidad and Tobago; 2 are subnational: Cayman Islands and Jamaica).<sup>4,17,18,21</sup>

## Capacity-Building Activities

The AC3 focuses on capacity-building efforts in the field of cancer registration in the Caribbean by hosting a series of special topics and training sessions during biannual scientific meetings and other supporting initiatives.<sup>4,18,19</sup> Five scientific meetings have been conducted to date since 2007. During the 2007 and 2008 AC3 meetings, presentations by cancer registrars provided an overview of the cancer burden in the Caribbean region.<sup>17,18</sup> During the 2010 meeting, rationale for cancer registration, the different types of cancer registries, and the relevant steps for planning and implementation of a cancer registry were discussed.<sup>4</sup> The 2012 meeting provided another opportunity for presentations of national cancer registry data from 4 cancer registries in lower–middle-income countries (Kenya, Guyana, Jamaica, and Trinidad and Tobago).<sup>5</sup> Cancer statistics were presented that revealed the reality of cancer burden in these Caribbean countries.<sup>5</sup> Cancer registration activities concluded with a satellite meeting with the NCI.<sup>5</sup>

To continue what the AC3 has accomplished, the information learned thus far, and to address current needs, an AC3 cancer registry workshop was organized in 2013 as a preconference to the annual meeting of the Caribbean Public Health Agency (CARPHA).<sup>22,23</sup> The primary purpose of the 1-day meeting was to amplify, promote, and sustain Caribbean scientific research through collaborations with cancer registries.<sup>22</sup> The objectives of the workshop were to describe the applications and utilization of cancer registry data in collaborative research and to discuss the importance of policy decision-making and its impact on existing or developing national cancer registries and cancer control.<sup>22</sup> The workshop united existing and aspiring cancer registrars, pathologists, clinical and biomedical scientists, representatives of public health organizations, and cancer advocates.<sup>22</sup> It also presented opportunities for dialogue and collaboration between English- and French-speaking Caribbean nations.<sup>22</sup>

This initiative was further reinforced by the 2014 Cancer Surveillance in the Caribbean meeting, a joint effort of several stakeholders that included the NCI, the CARPHA, the US Centers for Disease Control and Prevention, the International Agency for Research on Cancer (IARC), the Pan American Health Organization (PAHO), the US Northern Command, and the AC3.<sup>24</sup> As of this publication, the AC3 2014 scientific meeting was the most recent gathering to discuss strategies in the way forward toward better cancer registration and collaborative research for the Caribbean region.<sup>21,25</sup>

### **Established Cancer Registries**

Of the 30 nations and territories in the Caribbean region, 12 have established cancer registries, 6 of which have existed for more than 30 years (Puerto Rico, Jamaica-Kingston, Cuba, The Netherlands Antilles, Bermuda, and Martinique) and 1 for 20 years (Trinidad and Tobago), whereas all others have been in operation for 5 to 15 years (Table 1). Of these, 4 cancer registries (Cuba, Jamaica-Kingston, Martinique, and Puerto Rico), representing 14.4% of the regional population, have contributed high-quality incidence data published by the World Health Organization (WHO).<sup>26</sup>

Based on discussions from the workshop, emerging cancer registries in other countries (eg, Anguilla, St Kitts and Nevis, St Lucia, the Bahamas and the Cayman Islands) may be hampered by challenges, including limited training opportunities, limited staff availability and qualifications, inadequate information technology support, and transportation difficulties for data retrieval. Other challenges include lack of diagnostic facilities, lack of pathologists, and long reporting delays compounded by poor verification of data, lack of formal death certification, and lack of support from ministries of health. The latter is critical to ensure sustainability of cancer registries and their role in developing and evaluating cancer control strategies.<sup>27-29</sup>

### **Surveillance Estimates and Quality of Data**

The Caribbean region ranks fifth worldwide for cancer incidence and fourth for mortality (185.4 and 102.0 per 100,000 per year, respectively; Fig 2).<sup>2</sup> However, disparities exist in the quality of available cancer data, because 4 Caribbean nations have high-quality national or regional cancer incidence data, whereas 2 nations have complete, high-quality cancer

mortality data (Table 2).<sup>2</sup> Furthermore, for countries without existing cancer registries or those with newly established registries, cancer statistics are typically derived from estimates of the WHO compiled from a combination of nationally reported mortality data and hospital-based data.<sup>2</sup> Therefore, it is possible that under-reporting is occurring for some Caribbean nations, thus underlying the need for indigenous cancer registry data to accurately reflect the burden of cancer in the region.<sup>2</sup>

### Available Research Data

Deeper insight into cancer registration in the Caribbean and its potential perspectives was achieved through a description of available data provided by countries to CARPHA. Highlights from these data included the high prevalence of smoking in some countries (although the general belief is that smoking has a very low prevalence throughout the Caribbean) and a high prevalence of alcohol intake.<sup>30,31</sup> Taken altogether, the data suggest an increased risk for the development of noncommunicable diseases, including cancer, with these conditions representing the top 10 causes of death during the last decade in the Caribbean. Although some research on environmental carcinogens has been documented, such as the prostate case-control study in Guadeloupe, the region still lacks research in this domain.<sup>32</sup> Other gaps in the data include cancer morbidity and survival rates, clinical management, and population screening rates for specific cancers (cervical, breast, and colon).

### Usefulness of Cancer Surveillance Data in Research Collaborations

The usefulness of cancer registries in collaborating with research for population-based case-control studies was also described (Fig 3). For example, data from registries allow researchers to plan or estimate the number of expected cases, identify the main hospitals where cases may be found, or identify patients for recruitment into research studies. During the study, data can be cross-checked with the registry to ensure coverage. Registry data are also useful for checking on selection bias in research studies. If the registry also conducts follow-up for cases, then it can provide the study with additional data on outcomes. Examples of such collaborative work were illustrated by an ongoing study investigating socioeconomic inequalities in cancer incidence and mortality in Martinique and Guadeloupe as well as AC3 collaborations involving the cancer registries in Trinidad and Tobago and Guyana.<sup>33</sup> Analyses of data, issuing from these AC3 collaborations, have been conducted or are near completion for prostate, breast, and head and neck cancers.<sup>34–39</sup> Such findings have helped shed insight into the burden of cancer and differences in outcomes in comparison with US or global cancer statistics. Furthermore, the important role played by cancer registries, in terms of research or public health intervention, was illustrated by the French Caribbean island of Martinique.<sup>40–46</sup> There, long-existing, precise registry data have informed analytical studies on several cancers and have helped assess the environmental and occupational health risks or evaluation of medical practice and local screening programs for major sites.<sup>40–46</sup>

Optimizing fruitful surveillance and research collaboration requires certain legal and ethical environments, as well as specific infrastructure and organization. Of particular importance is a properly defined and functioning information system. This should not necessarily be

electronic, but indicators must be well defined, with appropriate resources for sustaining data collection and reporting from both public and private health care sectors. In addition, standard protocols, and best practices, relying on evidence-based medicine, should be implemented. Several presenters during the workshop provided evidence for using cancer registries as building blocks for collaborative research, with particular emphasis on capacity building in developing regions. Surveillance data were also demonstrated to have use in driving research studies. For example, the purpose of any cancer registry should include producing more stable and accurate rates, greater access to data, and the possibility to investigate geographical variability (Fig 3). However, a registry would also be valuable to investigate the quality of care, possibly by looking at stage at diagnosis, or whether screening is being performed, as well as examinations of social issues and barriers to screening and treatment. Although separate research studies may be required for some of these, by working with registry teams, the data could be combined to provide a broader picture. Population-based cancer registries represent the gold standard, but they can also be used to examine rates standardized by age, age-specific incidence, sex ratios, rates in different ethnic groups and migrants, time trends, and survival.<sup>47–49</sup> These data could then be used in health care planning and monitoring, as well as to inform policies, guide planning, and, once the knowledge of trends is available, to project treatment outcomes. When they are used to help validate current cancer mortality data, cancer registry data can also illuminate areas for research.

Proving the usefulness of the data from a cancer registry is a powerful way to influence the public and to help ensure continued future funding. Linking surveillance with research outcomes is another way to guarantee continued collaboration and, perhaps, registry sustainability. For example, registry data can be used to evaluate improved outcomes from a range of research projects: public health interventions, comorbidity investigations, examination of the quality of diagnosis, treatment and follow-up care, epidemiological research, genetics, community impact, and survivorship, among others.

### **Policy Decision-Making and Its Impact**

A general consensus suggested that the role of policy makers in institutions and governments is vital, because financial resources are essential to sustain a registry, especially in the current economic climate. This must be considered at a time when countries are grappling with salary payments and consideration of the sustainability of a registry may not be seen as a priority. Barbados represents an example of how surveillance might be made more cost effective.<sup>50,51</sup> It has a cancer and a multi-noncommunicable diseases registry, including data on stroke and acute myocardial infarction.<sup>50</sup> Having 3 components to a registry can provide economies of scale, where separate registries may become too expensive. Shared leadership, office space, and training, combined with administrative, statistical, and epidemiological support across all registry components, can reduce costs. However, financial challenges remain because, as is similar across many countries, cancer registries operate without much publicity and the work they conduct may be largely unknown.<sup>24</sup> Registry funds rarely include a line item for marketing or public advocacy, and, in many Caribbean countries, cancer is a taboo subject not openly discussed, so a registry

rarely gains much public recognition and, hence, financial security for a cancer registry becomes even more precarious.<sup>24,51</sup>

A stepwise approach was proposed by the CARPHA to improve cancer registration in the region: strengthen existing registries and establish mechanisms to improve reporting (even if merely reporting on the type of data collected to date), perform situation analyses of what currently exists, outline a strategic plan in which strengths and weaknesses are identified, and assist with data analysis and reporting at least annually.

## Discussion

A need exists in the Caribbean for a common, unified response and for more active regional collaboration in terms of cancer surveillance and research, which takes into account territorial specificities (similarities and differences) and implicates both scientific and governmental bodies. However, Caribbean countries vary in their urgency and capacity to respond to increasing regional rates of cancer burden.<sup>4,5,22,24</sup> Sparse and incomplete data, aging populations, high-cancer risk prevalence, low/limited resource settings, as well as high frequencies of cancer-related deaths or cancers with poor prognoses, or the lack of targeted cancer care and prevention strategies, highlight the importance for progress in cancer surveillance and research.<sup>4,5,22</sup> This is even more true when it comes to building synergy between these 2 fields for targeting efficient cancer control and management strategies in the Caribbean.<sup>4,5,22</sup>

Conscious of the need to move forward in the cancer field, different stakeholders in the region have joined their efforts to address challenges and opportunities for cancer surveillance and research in the Caribbean.<sup>4,5,22,24,25</sup> Prior regional scientific meetings have helped provide better insight on the current state of surveillance infrastructure and collaborative research initiatives and outcomes.<sup>4,5,17,18,22,24,25</sup> Although collaborations between research and surveillance have benefits and exist in the regional context, they are still mostly deemed insufficient.<sup>4,5,17,18,22,24,25</sup> The state of collaborative research between registries and medical/research teams still remains limited and policymakers are not fully convinced of the need to promote such endeavors.<sup>27</sup>

Population-based cancer registries allow a specific type of surveillance vital for delivering quality national data to provide a precise description of the degree of cancer burden in a country. Without such data, knowledge about the degree of cancer burden may be very limited. Furthermore, it would be difficult, if not impossible, to develop, implement, monitor, and evaluate cancer strategies for prevention and disease management without cancer registries due to their continuous provision of national data.<sup>14,27–29</sup> These data are important for cancer control and essential to better guide research.<sup>14,27–29</sup>

Most Caribbean nations with registries have managed to achieve an infrastructure that encourages collaboration with research; however, major challenges still exist to sustaining registry activity, addressing confidentiality concerns in a small island setting, maintaining economic viability and optimizing the quality of their data due to a combination of poor documentation and lack of electronic health information systems.<sup>22,24</sup> For example, in



Barbados, existing challenges include incomplete or poorly documented medical records, limitations in retrieval of death records, and suboptimal passive reporting from the private medical sector.<sup>22</sup> One of the fundamentals will be stimulating better awareness of available tools and resources as well as resource optimization between existing Caribbean research networks, cancer registries, and international organizations.

Other Caribbean countries, despite acknowledging their need, experience challenges from limited cancer registry expertise or infrastructure, and/or a lack of support from governmental bodies.<sup>22,24</sup> Many of these countries have important cancer burdens despite their small geographical and population sizes.<sup>2,4,5,17,18,22,24</sup> For example, in St Lucia, which has had a hospital-based cancer registry in operation since 1997, almost one-half of the cases registered in 2002 were identified from death certificates alone, and cancer has been the leading cause of death on the island since 2006.<sup>22</sup> Fully registered cases often lack follow-up information, partly due to decentralization and duplication of patient records within the public health care sector and partly because of the number of patients sent overseas for treatment.<sup>22</sup> In addition, despite being operational for more than 15 years, the St Lucian registry is not perceived as being indispensable.<sup>22</sup> Implementation of a national cancer control program through a multisectoral approach, including more collaboration with international agencies and more experienced registries, may help address some of these issues.

To help advance the cancer registry agenda, fledgling registries can take advantage of civil society organizations. For example, in the Cayman Islands, the Cayman Islands Cancer Society has played a significant role in lobbying for the registry.<sup>22</sup> In Barbados, local civil society organizations have been strong supporters of the national cancer registry, working in partnership with them to ensure comprehensive data capture.<sup>22,24</sup> The potential role that civil society organizations can play in reaching communities to build awareness and create grass roots advocates for registries is important. They also provide a valuable link between potential community advocates and decision-makers in ministries of health.

Further solutions lie in developing a strategic plan that includes setting standards for reinforced sustainable population research for the Caribbean. This implies identifying intercountry and intracountry specificities, needs, and priorities as well as existing tools, resources, and stakeholders. Developing standards also requires improved use of existing information systems, the generation of higher-quality cancer data, the implementation of best practice protocols, and more efficient communication. Because of the strong advocacy for surveillance guiding targeted research, the strategic regional research plan will also need to stimulate the development of collaborations in the region. Such collaborations, initiated between the various stakeholders/actors in the field of oncology (existing/aspiring cancer registries, research and medical teams, governmental and institutional policy makers and other cancer advocates/research teams at the local, regional and international levels), will create opportunities for dialogue on the rationale and role of cancer registration, the value, application, and utilization of cancer registry data in collaborative research, the illustration of the outcomes of cooperative work, and the importance and impact of policy decision-making.

Capacity building will be imperative to facilitate research collaboration through linkages between cancer registries, clinical personnel, research teams, and diverse data sources (eg, histopathology, comorbidity), because even well-established cancer registries experience underutilization of their data as a research resource.<sup>22,24</sup> For example, the French Caribbean islands of Martinique and Guadeloupe need to promote their scientific activities to develop collaboration between these French Caribbean registries and other Caribbean islands with populations of similar ethnic and environmental patterns.<sup>22,24</sup> Another important issue for some islands is their small population sizes, which make it difficult to examine less common cancer sites.<sup>22</sup> Collaborative studies involving several Caribbean nations can overcome this limitation; however, differences in social and cultural contexts, in economic development, and lack of data on ethnicity in the French registries may be significant barriers to implementation of such collaborative studies.

To overcome some of these barriers, the AC3 has integrated cancer registries (7 Caribbean and 2 African) as members of their network and has constituted a broad-based platform for education, training, and research on all cancer aspects (etiology, screening, prevention, treatment, and survival) in populations of African descent. During the 2012, 2013, and 2014 AC3 Caribbean meetings, the desire to see an increase in indigenous cancer statistics reports from the region was unanimous and regional analyses of cancer statistics were prioritized as one of its planned activities.<sup>5,22,25</sup> Collaborative efforts between the cancer registries represented within the AC3 are currently in motion. At the forefront of collaborative research in the region with 45 published articles, the AC3 has several initiatives in progress for regional cancer data analyses, foundations for research biospecimen banks, networking, collaborating, standardizing, supporting, and optimizing existing cancer surveillance and research opportunities, with the main objective of establishing a global cancer network within the Caribbean region.<sup>21</sup> The 2013 and 2014 AC3 cancer registration meetings in Barbados and Martinique provided a much-needed opportunity for networking between research investigators, cancer registrars, and health care professionals, providing insight into the possibility of collaborative opportunities between cancer registries within the wider Caribbean region.<sup>22,25</sup> These meetings also emphasized the importance of a regional cancer network in the Caribbean to help promote collaborative research and to obtain more effective and efficient cancer control, as the Caribbean moves toward optimization of these registries for scientific excellence in cancer research.<sup>22,25</sup>

Existing research–cancer registry collaborations are paving the way, and organizations like the AC3, NCI, IARC, and PAHO facilitate and promote such endeavors.<sup>4,5,17,18,21,22,24,25</sup> In 2011, heads of state and governmental representatives assembled for a high level UN meeting on the prevention and control of noncommunicable diseases.<sup>52</sup> The meeting culminated with a political declaration, thus highlighting the need to reduce risk factors, strengthen national policies and health systems, build international cooperation, including collaborative partnerships, promote research and development, as well as implement systems for monitoring and evaluation to lessen the growing burden of noncommunicable diseases.<sup>52</sup>

Because cancer is a major noncommunicable disease that impacts morbidity and mortality in the Caribbean, cancer surveillance must be included as a key component in the global

monitoring framework for noncommunicable disease prevention and control developed as a result of the political declaration of the United Nations on noncommunicable diseases. Therefore, Caribbean countries are obligated to collect reliable data on cancer to facilitate reporting on these global indicators for noncommunicable diseases.<sup>22,24</sup> Research on cancer is also limited in the Caribbean region and is greatly needed to facilitate a better understanding of this problem in the area, with a view to improving care and treatment as well as to guide the implementation of interventions for cancer prevention and control.<sup>4,5,17,18,21,22,24,25</sup>

The regional agency, the CARPHA, supports public health surveillance and research in the English- and Dutch-speaking Caribbean.<sup>53</sup> Working with its 23 member states, as well as with international partners, the agency is committed to strengthening the scientific evidence on cancers and other diseases of public health importance as a means of improving public health in the region.<sup>53</sup>

The NCI has made significant investments to international cancer research, training, and other programs, with the goal of reducing the global cancer burden.<sup>54</sup> In 2011, these activities were formalized and coordinated via the creation of the Center for Global Health, which works to address the complex global challenges of cancer.<sup>54</sup> One of the top priorities of the Center for Global Health is strengthening US national and international partnerships for collaborations in global health research, cancer research, prevention, and control relevant to developing countries.<sup>54</sup>

To pursue these goals, the NCI performed several site visits in the Caribbean with the aim of learning about the available infrastructure and priorities for cancer control planning.<sup>24</sup> As a result, the NCI partnered with national, international, and regional stakeholders to plan initiatives to address the issue of cancer surveillance and registration for the Caribbean.<sup>24</sup> The NCI is also a partner in the global initiative for developing cancer registries in low- and middle-income countries, which is led by the IARC and implemented through regional hubs that provide technical and scientific support, deliver tailored training for population-based cancer registration, advocate for cancer registration, affiliated associations and networks, and coordinate international research projects.<sup>24</sup> Furthermore, the US NCI has partnered with the CARPHA, the PAHO, other US federal agencies as well as the AC3, to plan a stakeholder meeting for cancer surveillance to stimulate the strengthening of cancer registration and collaborative research in the Caribbean, to encourage the strategic use of information for national cancer control plans and programs, and to discuss strategies for moving forward.<sup>24</sup> All of these activities will contribute to an overall strategic plan for the development and strengthening of cancer registration for the region.

## Conclusions

Capacity building, resource optimization and sustainment, as well as collaboration and communication between cancer surveillance and research teams, are key to obtaining robust and complete cancer surveillance data for the Caribbean region and advancing cancer control through collaborative research. The motto remains that we must collaborate to grow.

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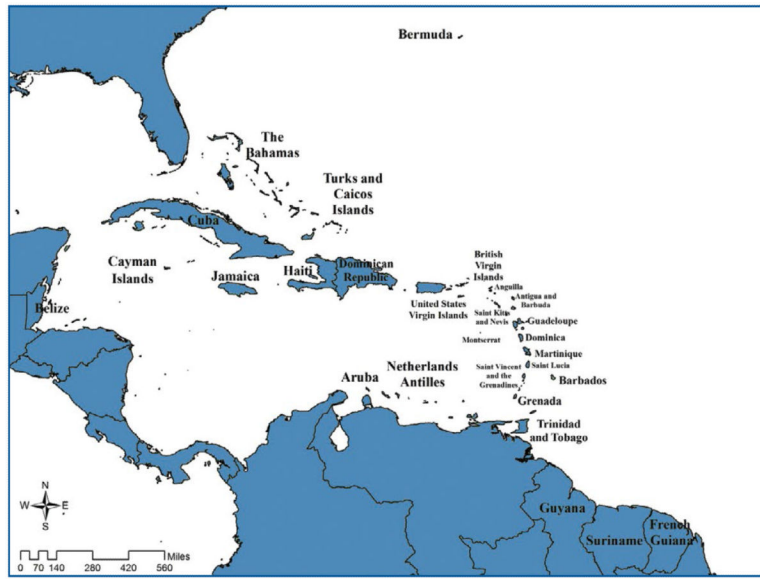
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**Fig 1.**  
Map of the Caribbean.

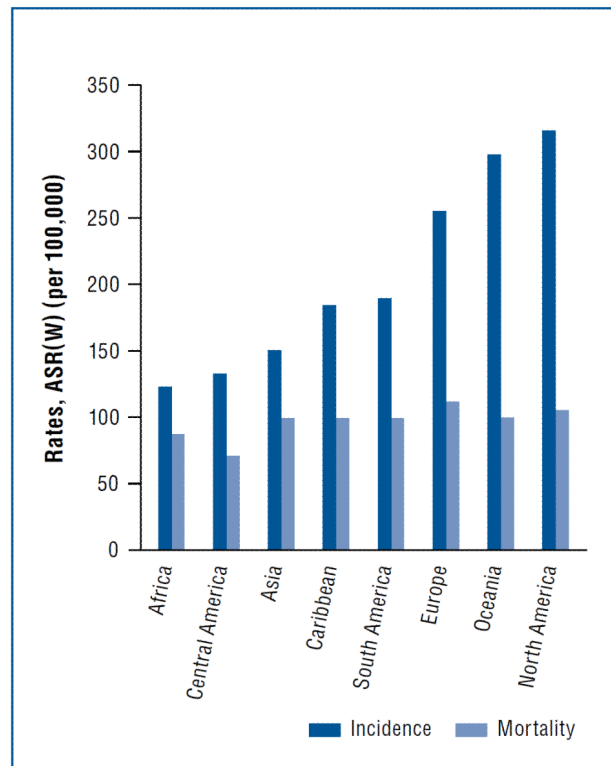
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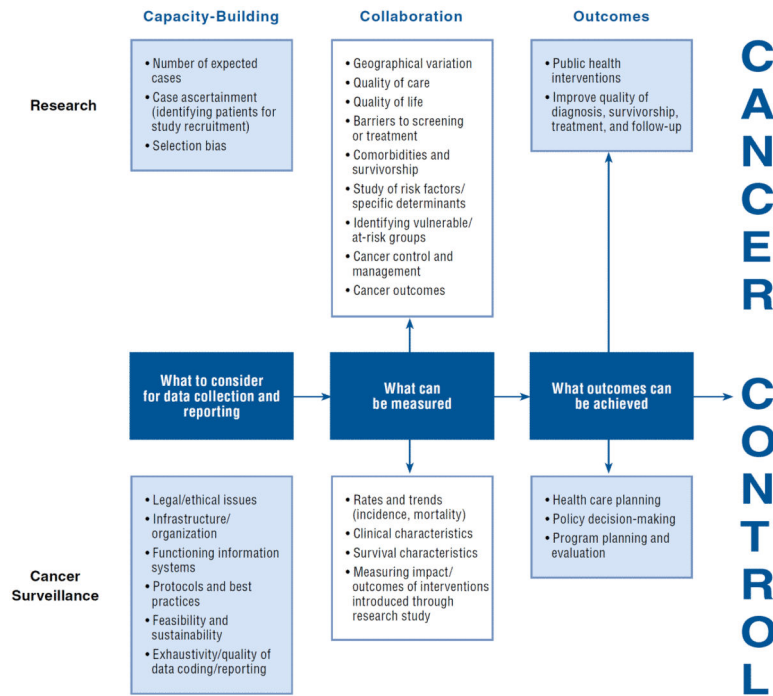
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**Fig 2.** ASR(W) of and mortality from all cancer sites per 100,000 per year by world region. The Caribbean region is defined as the Bahamas, Barbados, Cuba, Dominican Republic, Guadeloupe, Martinique, Haiti, Jamaica, Puerto Rico, and Trinidad and Tobago. ASR(W) = world age-standardized incidence rate. Data from reference 2.



**Fig 3.** Schematic of how surveillance data can be used to drive research studies through collaboration to promote cancer control.

**Table 1**

## Inventory of Established Cancer Registries in the Caribbean

Country	Type of Registry	Year of Establishment	Estimated Midyear Population <sup>12</sup>
Puerto Rico	National	1951	3,688,000
Jamaica <sup>a</sup>	Urban	1958	1,453,248
Cuba	National	1964	11,266,000
Netherlands Antilles <sup>b</sup>	National	1977	199,929
Bermuda <sup>c</sup>	National	1979	69,000
Martinique	National	1983	404,000
Trinidad and Tobago	National	1994	1,341,000
Guyana	National	2000	800,000
French Guiana	National	2005	249,000
Guadeloupe	National	2008	466,000
Barbados	National	2010	289,000
Cayman Islands	National	2010	54,000

<sup>a</sup>This registration occurs in urban areas alone (Kingston and St Andrew).

<sup>b</sup>Includes 6 Dutch-Caribbean islands: Curacao, Aruba, Bonaire, Saba, St Eustatius, and St Maarten.

<sup>c</sup>Underwent restructuring in 2004 and relaunched in 2008.

**Table 2**

## Quality of Cancer Data in the Caribbean

Availability	N	Caribbean Country
<b>Incidence Data</b>		
High-quality national or regional data	4	Cuba Martinique Puerto Rico Jamaica
National data (rates)	1	Trinidad and Tobago
Regional data (rates)	0	—
Frequency data	0	—
No data <sup>a</sup>	9	Bahamas Barbados Belize Dominican Republic Guadeloupe French Guiana Guyana Haiti Suriname
<b>Mortality Data</b>		
High-quality complete vital registration	2	Bahamas Cuba
Medium-quality complete vital registration	8	Barbados Belize Guyana Guadeloupe Martinique French Guiana Puerto Rico Trinidad and Tobago
Low-quality complete vital registration	4	Dominican Republic Haiti Jamaica Suriname
Incomplete or sample vital registration	0	—

Availability	N	Caribbean Country
Other sources <sup>b</sup>	0	—
No data	0	—

Data from reference 2.

<sup>a</sup>Not all cancer data originating from registries and other sources in some Caribbean islands have been referenced and evaluated by the International Agency for Research on Cancer.

<sup>b</sup>Cancer registries, verbal autopsy, and surveys, among others.

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