Cancer Control in Small Island Nations 4

Advancing cancer care and prevention in the Caribbean: a survey of strategies for the region

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Cancer is now the second leading cause of death in the Caribbean. Despite this growing burden, many Caribbean small island nations have health systems that struggle to provide optimal cancer care for their populations. In this Series paper, we identify several promising strategies to improve cancer prevention and treatment that have emerged across small island nations that are part of the Caribbean Community. These strategies include the establishment of a Caribbean cancer registry hub, the development of resource-appropriate clinical guidelines, innovations in delivering specialty oncology services (eg, paediatric oncology and palliative care), improving access to opioids, and developing regional training capacity in palliative medicine. These developments emphasise the crucial role of public–private partnerships in improving health care for the region and show how fostering strategic collaborations with colleagues and centres in more developed countries, who can contribute specialised expertise and improve regional collaboration, can improve care across the cancer control continuum.

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This is the fourth in a **Series** of five papers about cancer control in small island nations

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Introduction

Cancer presents a major public health challenge for the Caribbean. Although cancer incidence rates are often lower in the Caribbean than those in more developed countries, the proportion of patients dying from cancer is extremely high. In fact, among Caribbean small island nations for which GLOBOCAN 2018 data are available, the mortality-to-incidence ratios for cancer in Caribbean countries are approximately more than double that of the USA (table 1). For some Caribbean countries, annual mortality rates for breast and prostate cancers are higher than those in the UK and the USA (table 2), although there is also a considerable difference between the UK and the USA in mortality for these cancers. These high mortality rates might be due to the large number of patients presenting with advanced disease. For example, among Caribbean women who have been newly diagnosed with breast cancer, only 11% in Jamaica,[4] 10·6% in The Bahamas,[5] and 11·2% in Trinidad and Tobago[6] present with stage I breast cancer, compared with 48% in the USA.[7] No further data are available throughout the rest of the Caribbean, and indeed, few comprehensive sources of data are available across the Caribbean that address clinical and pathological characteristics of cancer cases or surveillance data on cancer incidence and mortality. Across the region, the resources and infrastructure needed to appropriately care for patients with cancer once diagnosed can also contribute to poor clinical outcomes.[8] Cancer is now the second leading cause of death in the Caribbean, with an age-adjusted rate of 132·95 deaths per 100 000 population, which is second only to cardiovascular disease at 199·44 deaths per 100 000.[9,10]

Small island nations is a UN classification for developing small island countries that share specific social, economic, and environmental vulnerabilities.[11] Although the development and implementation of effective cancer control plans in low-income and middle-income countries (LMICs) is often challenging due to limited resources and inadequate infrastructure, there are additional hurdles that must be addressed within small island nations, regardless of World Bank income classification. These include geographical isolation, small population size, and insufficient human resources.[12] Tackling these challenges will require changes that engage all aspects of small island nations' health-care systems, including health-care financing, governance, workforce development, health information technology, and ensuring access to essential resources.[13]

Although development and implementation of comprehensive cancer plans at the national level continues to prove daunting within most small island nations in the Caribbean, there are emerging efforts that are successfully tackling important components of the cancer control continuum. However, characterising innovative strategies to improve cancer prevention and treatment is difficult because of the dearth of published reports on these emerging initiatives. In the third paper of this Series,[12] we outlined the health-care context of the Caribbean countries and territories, including the unique political, economic, and social context of the region with respect to health, non-communicable disease (NCD) policy, and cancer control planning and screening. To complement this paper, we decided to collect and disseminate information regarding promising strategies that can be replicated elsewhere in the Caribbean by engaging key informants throughout the Caribbean Community (CARICOM) small island nations to identify and describe innovative strategies addressing various aspects of the cancer control continuum in their

	Population, 2018[1]	Cancer incidence (per 100 000)	Age-standardised incidence rate (per 100 000)	Mortality-to-incidence ratio
Anguilla	17 000	..	..	..
Antigua and Barbuda	103 000	..	..	..
The Bahamas	399 000	933	181·4	0·517
Barbados	286 000	1245	247·5	0·579
Belize	382 000	358	132·4	0·561
Bermuda	71 000	..	..	..
British Virgin Islands	28 000	..	..	..
Cayman Islands	60 000	..	..	..
Dominica	74 000	..	..	..
Grenada	108 000	..	..	..
Guyana	782 000	751	105·4	0·627
Haiti	11 113 000	12 366	142·3	0·721
Jamaica	2 899 00	7348	203·7	0·646
Montserrat	5 000	..	..	..
Saint Kitts and Nevis	44 000	..	..	..
Saint Lucia	180 000	376	157·7	0·590
Saint Vincent and the Grenadines	110 000	..	..	..
Suriname	568 000	1042	172·6	0·599
Trinidad and Tobago	1 373 000	3369	177·4	0·590
Turks and Caicos Islands	28 000	..	..	..
UK	66 573 000	446 942	319·2	0·399
USA	326 767 000	2 129 118	352·2	0·290

Some cells in this table are empty because the data for these countries do not exist in the cited databases.

Table 1: **Annual cancer incidence and mortality-to-incidence ratios[2] in the Caribbean, UK, and USA**

	Breast cancer mortality rate (female)	Prostate cancer mortality rate (male)
Anguilla, 2016[1]	8·00	49·50
Antigua and Barbuda, 2016[1]*	44·70	50·40
The Bahamas,2014[1]*	29·00	36·40
Barbados, 2016[1]	..	..
Belize, 2016[1]*	14·50	38·10
Bermuda, 2016[1]	15·70	21·80
British Virgin Islands, 2016[1]	..	..
Cayman Islands, 2016[1]	..	..
Dominica, 2015[1]	17·10	91·40
Grenada, 2016[1]	43·50	90·30
Guyana, 2014[1]*	22·10	42·30
Haiti, 2016[1]	..	..
Jamaica, 2014[1]*	23·40	42·70
Montserrat, 2016[1]	..	99·80
Saint Kitts and Nevis, 2016[1]	31·30	89·90
Saint Lucia, 2016[1]	..	..
Saint Vincent and the Grenadines, 2015[1]	22·60	115·20
Suriname, 2014[1]*	18·50	38·60
Trinidad and Tobago, 2016[1]	..	..
Turks and Caicos Islands, 2015[1]	11·40	4·90
UK, 2014[3]	41·15	57·22
USA, 2016[1]	15·40	11·50

Rates have been age-adjusted and represented per 100 000 population. Some cells in this table are empty because the data for these countries do not exist in the cited databases. *Rates have been corrected for under-registration.

Table 2: **Breast and prostate cancer mortality rates for all ages in the Caribbean, UK, and USA**

countries. Specifically, we have focused on CARICOM member and associate member states as part of data collection.[14]

A substantial proportion of data concerning cancer control and care in the Caribbean are not available in the public domain. Our method thus included discussions with key informants from ministries of health, clinical sites, and cancer-related non-government organisations (NGOs) throughout CARICOM countries, and subsequent requests by our team of authors to these key informants for specific data on cancer control activities. Through these data collection efforts, we have identified a series of promising initiatives for cancer care and control within these countries, and situate these within the larger context of improving cancer care and prevention in the Caribbean. Key initiatives include establishment of a Caribbean cancer registry hub, the development of resource-appropriate clinical guidelines, innovations in delivering specialty oncology services (eg, paediatric oncology), developments in improving access to opioids, and developing regional training capacity in palliative medicine. Although we have made attempts to comprehensively identify cancer control initiatives across CARICOM countries, the case studies presented in this Series paper should be interpreted as promising and emblematic initiatives for the region and not as a comprehensive list of all initiatives needed for effective cancer control within the Caribbean.

Improved cancer data for public health use: development of a Caribbean cancer registry hub

Access to reliable, high-quality information on the burden of cancer is needed in the Caribbean so that effective policies for cancer control can be developed, implemented, and monitored. As table 1 shows, there are few systematic data on incidence and mortality for all cancers across the Caribbean region, although cancer-specific mortality rates have been published by the Pan American Health Organization (PAHO).[1] Table 2 shows the annual prostate and breast cancer mortality rates across the Caribbean using PAHO data, with data from the UK and the USA provided as a reference. However, annual prostate and breast cancer mortality rates for some Caribbean countries are unknown (table 2). Population-based cancer registries are a fundamental aspect of cancer control, providing the necessary data on incidence and mortality that can lead to informed action by local governments. Despite their feasibility even in resource-limited settings,[15] a situation analysis[16] showed that fewer than ten Caribbean countries and territories

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	Human Development Index	Cancer registration history[17]*	Future plans for cancer registry*	National cancer control or NCD plan[18]
Anguilla	High	..	To join the proposed OECS joint cancer registry	..
Antigua and Barbuda	High	..	Hospital-based registry in development; implement a PBCR and be part of a pooled cancer registry	NCD plan, 2015–19
The Bahamas	High	Hospital-based cancer registry	To extend to a PBCR	..
Barbados	High	National registry since 2010, as part of an NCD surveillance system	..	NCD plan, 2015–19
Belize	Upper middle	..	To implement a national registry, complementing regional data collection and electronic reporting	..
Bermuda	High	National registry since 1979, included in CI5 VI	..	..
British Virgin Islands	High	..	To implement a PBCR and join the proposed OECS joint cancer registry	..
Cayman Islands	High	National as of 2010, using a self-reported system	..	..
Dominica	Upper middle	..	To join the proposed OECS joint cancer registry	..
Grenada	Upper middle	..	To implement a PBCR and join the proposed OECS joint cancer registry	NCD plan, 2013–17
Guyana	Upper middle	Registry activity since 2000	..	NCD plan, 2013–20
Haiti	Low	Cancer registry activity	..	..
Jamaica	Upper middle	Kingston and St Andrew Registry included in CI5 IIV and X–XI	National PBCR in development	Cancer Control plan, 2013–18; NCD plan, 2013–18
Montserrat	High	..	To join the proposed OECS joint cancer registry	..
Saint Kitts and Nevis	High	..	To join the proposed OECS joint cancer registry	NCD plan, 2013–17
Saint Lucia	Upper middle	..	To implement a PBCR and join the proposed OECS joint cancer registry	..
Saint Vincent and the Grenadines	Upper middle	..	To join the proposed OECS joint cancer registry	NCD plan, 2015–19
Suriname	Upper middle	Some cancer registry activity	..	Cancer Control plan in development, 2018–28, NCD plan, 2015–20
Trinidad and Tobago	High	National since 1994, with periods of inactivity	..	NCD plan, 2017–21
Turks and Caicos Islands	High	No registry activity	..	..

NCD=non-communicable disease. OECS=Organization of Eastern Caribbean States. PBCR=population-based cancer registry. CI5=Cancer Incidence in Five Continents. *Information on status of cancer registration (active or planned) is not published and was gathered through correspondence with the Caribbean Hub.

Table 3: **Cancer registration history and development in the Caribbean Hub countries**

have a population-based cancer registry, and only registries from Barbados, Jamaica, Guyana, and Trinidad and Tobago meet international quality standards (table 3). Because of the absence of available data for the region, only 13 of the CARICOM member and associate member countries (Antigua and Barbuda, The Bahamas, Barbados, Belize, Dominica, Grenada, Guyana, Jamaica, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Suriname, and Trinidad and Tobago) were included in the analysis, which highlights an urgent need for more comprehensive cancer surveillance data collection and distribution throughout the Caribbean.

Prioritising cancer control activities, including recommendations to establish registries, has been a focus in the Caribbean region.[19] There is a clear need for improved cancer data because only two registries from the Caribbean region (Martinique and Jamaica) were included in the most recent edition of Cancer Incidence in Five Continents, a publication of high-quality cancer registries worldwide.[20] In response to the paucity of data in the region, and because the global cancer burden is anticipated to nearly double by 2040,[12] the International Agency for Research on Cancer (IARC) Caribbean Regional Cancer Registry Hub was founded in 2015, and operates as a coalition of partners in the region. The Caribbean Hub is located within the Caribbean Public Health Agency (CARPHA) in Port of Spain, Trinidad and Tobago. It is one of six regional reference centres that have been established as part of the IARC-led Global Initiative for Cancer Registry Development (GICR), which is the first worldwide strategy to inform cancer control through establishing better platforms for data collection. The specific aim of the Caribbean Hub is to strengthen the systematic collection, availability, and use of cancer surveillance data to enable governments to better inform national cancer control plans.

IARC Hubs directly support in-country capacity building for cancer registration through technical training of registry personnel; consultancies through site visits and mentorship arrangements, including advice to governments; analysis to help produce scientific reports and guide policy development; and the formation of regional

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For more on **CARICOM** see https://www.caricom.org

For more on the **GICR** see http://gicr.iarc.fr

	Key activities	Partner organisations*
2014†	Situational analyses to review status of cancer registration; regional workshop in Aruba to discuss the formation of an IARC Caribbean Hub with stakeholders	Caribbean Public Health Agency; International Agency for Research on Cancer; Pan American Health Organization; US Centres for Disease Control and Prevention; US National Cancer Institute, National Institutes of Health
2015	Caribbean Cancer Control Leadership Forum held in Barbados to increase capacity in cancer control planning and implementation; The Caribbean Public Health Agency selected to host the Hub, with support from US partners; approval from the Caribbean Chief Medical Officers of Health for implementation of the Hub; site visit to the US Virgin Islands	Healthy Caribbean Coalition; North American Association for Central Cancer Registries; Union for International Cancer Control; Ministry of Health, US Virgin Islands
2016	Hub staff appointed; site visits to Barbados, Trinidad and Tobago, The Bahamas, and Jamaica; CanReg regional course, National Cancer Institute, Bethesda, MD, USA	Ministry of Health and Wellness, Barbados; Barbados National Registry for Chronic Non-Communicable Disease; The George Alleyne Chronic Research Disease Centre; The University of the West Indies; Ministry of Health, Trinidad and Tobago; Ministry of Health, Bahamas; Ministry of Health, Jamaica
2017	Development of standard operating procedure manual; follow-up visit to Jamaica; on-site technical support in CanReg5; evaluation of the quality and completeness of cancer registry data from Guyana and Trinidad and Tobago	African Cancer Registry Network; Ministry of Health, Guyana; GICRNet CanReg5 experts
2018	Inauguration of the IARC Caribbean Hub; site visit to British Virgin Islands; establishment of the IARC Global Initiative for Cancer Registry Development Collaborating Centre in Martinique; mortality SEER-Stat regional course, USA; coding and staging regional course, USA; proposal developed to implement a shared virtual cancer registry for the Organization of Eastern Caribbean States	Ministry of Health, British Virgin Islands; University Hospital of Martinique, Martinique; Organization of Eastern Caribbean States

IARC=International Agency for Research on Cancer. *Listed in chronological order of first involvement. †The Caribbean Hub was founded in 2015. The activity listed in the table for 2014 is planning activity in advance of the Hub's founding in 2015.

Table 4: **Key developments in the IARC Caribbean Hub**

networks to facilitate the exchange of information and sharing of expertise. From January, 2015, to the present (July, 2019), the IARC Caribbean Cancer Registry Hub completed six in-country site assessments (Virgin Islands, Barbados, Trinidad and Tobago, The Bahamas, Jamaica, and British Virgin Islands) to document the status of cancer registration and identify opportunities for improvement. A basic training workshop for 13 countries on the fundamentals of cancer registration (Anguilla, Aruba, The Bahamas, Barbados, Bermuda, British Virgin Islands, Cayman Islands, Grenada, Jamaica, Martinique, Puerto Rico, Saint Lucia, and Turks and Caicos Islands) and a workshop for five countries (The Bahamas, Belize, Guyana, Jamaica, and Trinidad and Tobago) on a cancer registration software, CanReg5, were also delivered by the Hub.

The Caribbean Hub has led workshops on registry data analyses using the statistical software SEER-Stat, and one workshop focused on improving standardisation and data quality (both attended by participants from Barbados, Bermuda, and Trinidad and Tobago). The Hub has evaluated data quality and coordinated technical support from cancer registry software experts for two Caribbean countries (Guyana and Trinidad and Tobago). A Caribbean Standard Operating Procedures Manual has been developed through consultation with Caribbean stakeholders and cancer registry experts with the aim of standardising procedures and best practices within registries for registry data collection and maintenance in the region.

As of July, 2019, research initiatives completed by the Caribbean Hub include an analysis of leading causes of cancer-related deaths in the Caribbean[16] and a 10-year trend analysis of deaths due to cancer, heart disease, cerebrovascular disease, and diabetes in 21 English and Dutch speaking Caribbean countries, Puerto Rico, and Virgin Islands from 2003 to 2013.[10] A summary of the main activities of the Hub since 2014 is provided in table 4. Funding for two dedicated, full-time Hub staff at the CARPH has facilitated the advancement of registry support to the region. With further public and private engagement in region-wide initiatives, substantial systematic improvement of cancer registry data across all Caribbean small island nations can be achieved.

Developing resource-appropriate cancer treatment guidelines for the Caribbean

Improved cancer outcomes in high-income settings are attributable to effective primary prevention strategies; early detection and diagnosis programmes; access to prompt, effective treatment; and situation-appropriate supportive and palliative care.[21,22] Optimal prevention and treatment strategies are described in clinical guidelines, but the resources needed to implement such clinical guidelines are routinely unavailable in clinical settings in LMICs, often leading to poor outcomes. Decision making and prioritisation of resources are particularly challenging in these settings, where important components for a standard level of care might be missing, health systems might be underfunded, and economic barriers to care can be widespread. Although small island nations are not always classified as LMICs, they share many of the resource constraints common to other LMICs, regardless of economic or World Bank income classification. In fact, the degree to which resources vary across the Caribbean

makes the establishment of single-tier guidelines for effective cancer control challenging, if not problematic.

One example of innovation in this area is the Breast Health Global Initiative (BHGI), which took on the challenge of developing clinical guidelines for breast cancer in LMICs while recognising the variation in resources available for each region or country, and which laid the foundation for resource-stratified guidelines for other cancers. From 2002 to 2013, the BHGI developed a series of guidelines to address the deficits prevalent in low-resource settings, built on the concept of resource stratification to guide breast cancer control planning across all resource settings.[23] Resource-stratified guidelines provide a framework for analysing health-care delivery systems as a basis for improving patient outcomes,[24,25] with the goal of tailoring evidence to the constraints of local health-care delivery systems. Such resource-stratified guidelines have since been adapted by many other leading cancer societies and organisations such as the National Comprehensive Cancer Network (NCCN), Asian Oncology Summit, World Bank, and American Society of Clinical Oncology.[25–33]

The NCCN Clinical Practice Guidelines in Oncology are now widely used throughout the world, including in many LMICs where some diagnostic tests and treatment approaches remain unavailable. NCCN has now created its own resource-stratified framework for breast and other cancers based on the BHGI methods and approach.[25,34] This framework outlines a rational approach for building cancer management systems to provide the highest achievable level of cancer care by applying available and affordable services in a logical sequence. Each resource level builds on the one before it, providing a framework for improving cancer care with incremental changes to the availability and allocation of resources.[35] As part of a joint project, in May, 2018, NCCN and members of the Caribbean Association for Oncology and Hematology (CAOH) adapted NCCN guidelines to create NCCN Harmonized Guidelines for the Caribbean. This exercise was initiated to create standardisation of current cancer treatment algorithms across the Caribbean to facilitate comparison of protocols based on various available resources and effective monitoring and evaluation of patient outcomes. Medical professionals from all Caribbean islands were invited to participate in a multidisciplinary team for each guideline. The specific NCCN Harmonized Guidelines for the Caribbean include diagnostic and treatment guidelines for prostate cancer, breast cancer, cervical cancer, colon cancer and colon cancer screening, rectal cancer, non-small-cell lung cancer, and multiple myeloma, the first of which were launched in August, 2018.[36]

A strength of these guidelines lies in the specific regional adaptation that these guidelines employed, which can be understood by practitioners, policy makers, ministers of health, and patient advocates, and which are targeted to address local resource-specific scenarios. For example, the NCCN Harmonized Guideline for breast cancer in the Caribbean (appendix p 1) provides alternatives to nuclear medicine scans when studies that require radioactive isotopes are unavailable. In 2018, the Harmonized Guideline for multiple myeloma was adopted as a national guideline by Trinidad and Tobago. The Ministry of Health will continue stakeholder consultations to refine the process of guideline implementation across the medical community. In general, harmonised guidelines represent a highly successful initiative to adapt clinical guidelines for cancer treatment to existing health-care resources among low-resource settings and represent the optimal care that LMICs should aspire to provide, offering pragmatic approaches to effective treatment options in resource-constrained settings.

See **Online** for appendix

Strategies for providing paediatric oncology services

Historically, the leading cause of childhood mortality in the Caribbean was infectious disease; however, cancer has now become the leading disease-related cause of childhood death in many Caribbean countries.[37] Often childhood cancer is neglected in broader discourses on cancer care and control because cancer is rare in children and does not typically receive a lot of research and investment. In developed countries, it represents less than 1% of all cancers, but in low-resource settings, where children can make up half of the population, the proportion of childhood cancer can be five times higher.[38,39] As with cancer care in the adult population, the capacity to deliver high-quality cancer care to small isolated populations is made difficult by numerous factors. The factors include a scarcity of adequately trained health professionals, the considerable expense of travelling to other islands, difficulty accessing cytotoxic medicines (keeping medicine in stock might not be cost-effective if the cancers are rare), and a scarcity of high-quality incidence data. Accessing radiotherapy will also often require treatment on another island, which results in travel, accommodation, and medical fees. Figure 1 shows estimates of the annual number of new cases in each jurisdiction by extrapolating from high-income country (HIC) incidence rates. Data from hospital-based registries in the English-speaking Caribbean islands show a 2-year survival rate of 55% compared with 85% in HICs.[37]

For more on the **CAOH** see https://www.facebook.com/caribbeanassociationofoncologyandhematology2017

Financial support for childhood cancer treatment varies widely across the Caribbean. For example, in Trinidad and Tobago, the Dominican Republic, and in public hospitals in Jamaica, essential diagnostic tests and treatment are financed through a combination of public health insurance, private insurance, and philanthropic funds. In Saint Lucia, families cover treatment costs directly or through private medical insurance. The Turks and Caicos Islands have a national insurance plan that provides wide coverage for children's needs, including access to care in centres of excellence overseas. Although

Figure 1: **Expected number of annual new cases of childhood cancer in selected Caribbean countries**
Reproduced from Gibson et al.[37]

health infrastructure is better developed in the Caribbean than in many other LMIC regions, it nonetheless also varies across jurisdictions. Paediatric oncologists and trained paediatric oncology nurses were, until recently, rare in the region. Access to radiotherapy facilities for small islands is scarce and building affordable and consistently available supplies of chemotherapy and supportive medications remains a substantial issue in delivering reliable cancer treatment. These challenges are exacerbated by varying population sizes in the Caribbean and often large distances between islands in the region (figure 1).

For more on **SCI** see http://www.sickkids.ca

Despite the many challenges involved, examples of progress are emerging. As these examples show, creating networks between existing paediatric cancer treatment units across the region is of great importance. These networks link paediatric oncology professionals to each other and to HIC institutions in twinning relationships that involve bidirectional exchange of knowledge, as well as providing philanthropic funding. The Central American Association of Pediatric Hematology Oncology (AHOPCA) established one of the first such twinning networks between treatment units across Central America with the University of Milan-Bicocca, Monza, Italy and St Jude Children's Research Hospital, Memphis, TN, USA. This was later expanded to include centres in the Dominican Republic and Haiti.[40] In 2012, the Dominican Republic launched the country's first paediatric palliative care programme with resultant improvements in quality of life (panel 1). Such an initiative provides an exemplary model for collaborative cancer care that other CARICOM countries could follow.

For more on **AHOPCA** see https://www.facebook.com/ahopca

The SickKids Capacity Building in the Caribbean Initiative (SCI) was formed in 2013 as a similar non-profit collaboration between the Hospital for Sick Children in Toronto, Canada, The University of the West Indies, and key hospitals and institutions from six countries in the English-speaking Caribbean (The Bahamas, Barbados, Jamaica, Saint Lucia, Saint Vincent and the Grenadines, and Trinidad and Tobago). SCI is funded through philanthropic contributions and aims to improve outcomes and quality of life for children with cancer and blood disorders. The initiative focuses on training and education to support early identification and treatment of childhood cancer in the region,[41] and has already had a positive effect across the cancer care continuum.[40,42]

Tracking patient outcomes is crucial to the design and evaluation of SCI interventions; therefore, institution-based paediatric cancer registries were established in all seven SCI centres (two in Jamaica), with data managers at each site trained to use REDCap, a secure online database platform.[43] Analysis of the first 5 years of data

from 2011 to 2015 showed inferior survival outcomes compared with survival outcomes from HICs. Findings of increased rates of treatment-related mortality among patients with leukaemia highlighted the need to modify leukaemia treatment protocols and improve supportive care measures.[37] SCI initiatives have also included the installation of telemedicine facilities in participating centres to facilitate regional communication. Regular educational rounds and case consultations are held through this infrastructure (panel 2).[42] Last, SCI launched an accredited Diploma in Paediatric Haematology/Oncology Nursing, with content delivered jointly by SickKids educators and lecturers at the University of The West Indies School of Nursing (panel 3). Together, these SCI initiatives have helped to build a community across the Caribbean dedicated to collaboratively improving childhood cancer outcomes.[42]

Despite these promising achievements, many obstacles remain. Medication supply remains a major challenge in delivering effective cancer care, which is exacerbated by unpredictable demand (particularly in smaller volume centres). Due to the small number of cases and cost of drugs, it is often difficult to stock cytotoxic drugs in adequate volumes, especially those with short expiration dates. There was also insufficient registry data before the establishment of the hospital registries to predict drug requirements. Moreover, unaffordability, and concerns about quality of medications (ie, generic medications that have not been tested or accepted internationally) contribute to the challenge of delivering effective cancer care. Many smaller jurisdictions are not part of either AHOPCA or the SCI, and thus might not be able to access their associated benefits.

Perhaps the greatest need to achieve coordinated cancer care is for the formal regionalisation of childhood cancer care delivery across the Caribbean. Ideally, a child on one of the smaller islands diagnosed with leukaemia could be stabilised (ie, a paediatric oncologist can ensure that all the tests required for diagnosis are completed and, if required, start some form of treatment such as steroids for all tumours, or vincristine for some solid tumors), rapidly transferred to a larger island's tertiary centre, where they will receive higher intensity treatments, and then transferred back to their local health provider for ongoing collaborative management. By concentrating specialised care but maintaining access to facilities across all Caribbean countries and territories, such regionalisation would ensure that all Caribbean children with cancer receive high-quality treatment in a timely and efficient manner while minimising disruption to families. Although such regionalisation would require formal agreements between governments and close cooperation between health centres, it would be an effective way to try to close the cancer survival gap between the Caribbean and the more developed countries of the Americas.

Panel 1: **Paediatric palliative care in the Dominican Republic**

Up until 2012, formal training in palliative care, palliative care programmes, and protocols did not exist in the Dominican Republic. However, in January, 2012,the Palliative Care and Metronomic Therapy Program was established at the Dr Robert Reid Cabral Children's Hospital, Santo Domingo. This represented the first paediatric palliative care programme in the country focused on children with cancer. Integrated care is provided by a paediatric oncologist with palliative care training, a palliative care nurse, an onco-psychologist, and two volunteers from a local non-government organisation, Fundación Amigos Contra el Cáncer Infantil, Santo Domingo. The goal of the Palliative Care and Metronomic Therapy Program is to promote comprehensive supportive and palliative care of children with cancer with the aim of maintaining stable disease, relieving pain and discomfort, improving functional and social activities, improving quality of life, and showing caregivers that their children are receiving adequate medical attention. The programme has provided specialised palliative care to 96 patients with non-curable disease, representing nearly 20% of newly diagnosed cases over 5 years. Admission to the programme is associated with intensified symptom management and psychosocial assistance, regardless of whether curative intent therapy is available, thereby benefiting all children with cancer. A local metronomic protocol consisting of ibuprofen, methotrexate and 6-mercaptopurine, is also commonly offered. Opioids, which were not prescribed before the start of the programme, have since become a mainstay of pain management.

Panel 2: **Case consultations across the Caribbean**

Case consultations in high-income country oncology centres are an integral part of patient care that ensures the best patient outcomes. For oncology services in low-income and middle-income countries (LMICs), there is often only one oncologist, rendering essential in-country patient discussions impossible. Therefore, telemedicine health-case consultations provide an important forum for case discussion of both rare and more common childhood cancers. The SickKids Capacity Building in the Caribbean Initiative has provided an opportunity for approximately 300 consultations over 5 years.
The consultations have taken many different forms, including:

- Discussion of challenging and rare cases
- Case consultations with educational updates
- Best treatment options in LMICs
- Best supportive care interventions in LMICs

All of these consultations have made a substantial effect on patient care delivery and outcomes. They have also improved communication between oncologists on different Caribbean islands. This communication reduces feelings of isolation and allows the sharing of solutions to common challenges between centres who understand the Caribbean health sector landscape. Communication done in this way fosters sustainability and will likely evolve into virtual case rounds for Caribbean centres.

Development of home-based and community-based models for delivering palliative care in the Caribbean

In the Caribbean, access to palliative care and pain relief for patients with cancer is very scarce.[44] Fortunately, there is now increasing recognition of the dire need to improve service provision in this crucial area of care. Some small island nations provide isolated services for palliative care[45] and examples of good practice do exist in the region (eg, hospice care is available in Trinidad and Tobago and Antigua and Barbuda, small NGOs provide

Panel 3: Training paediatric haematology and oncology nurses at the University of West Indies, Kingston, Jamaica

This programme was offered using a blended mode of delivery over a period of three semesters. The first and second semesters involved classroom learning, online activities, and clinical attachments to paediatric units within health facilities in Trinidad and Tobago, whereas the third semester was an internship in the students' respective countries at the institution where they work. To date, two cohorts totalling 26 participants from five Caribbean nations have been sponsored by the SickKids Capacity Building in the Caribbean Initiative to participate in the programme. One of the highlights was the development of change projects by each participant based on their individual experience of the programme. These projects were subsequently implemented at their local institution to improve care. Since the goal of the programme was to develop and scale up capacity among nursing personnel in the Caribbean region to better respond to the changing epidemiological profile and needs of children with cancers, the change projects were viewed as a strategic initiative to facilitate sustainability. Overall, the programme has allowed for improved interprofessional collaboration in the management of childhood cancers in the Caribbean region. For example, many graduates now support the training of medical students as they go through their clinical rotations.

For more on **Jasmine** see https://jasmine.ky

community-based care in Guyana, and community based care is available in Belize). We have identified two promising strategies for providing community-based palliative care.

The first example is an initiative in Barbados, which aimed to build capacity in palliative care using a primary-care focused approach. Barbados is classified as an HIC by the World Bank[46] with a high level of human development.[47] Like many countries in the Caribbean, health care is free at the point of access in the public setting.[48] In 2012, the Barbados Ministry of Health completed a palliative care needs assessment project.[49] The project resulted in recommendations that Barbados should offer a mixed model for palliative care, including the delivery of palliative care by general practitioners and community-based health-care workers and plans for a stand-alone hospice (unpublished). Palliative care in Barbados is primarily provided in a community setting through the work of NGOs, including the Barbados Association for Palliative Care and other faith-based organisations who provide hospice at home services, outpatient clinic services, and access to care equipment.[44]

Providing home-based care or community care is particularly important in a Caribbean setting where poverty, in conjunction with inadequate and often expensive transportation systems, combine to make access to palliative and supportive care services very difficult for many patients. Referrals to the home care team come principally from the island's main public hospital. First visits to the patient and family are done by a team consisting of a primary care physician and a nurse or social worker. The teams aim for consistency and often visit in pairs with one member of the team remaining consistent across a patient's journey. Together, the teams see about 50 new patients per year, with an average length of stay on the service of about 3 weeks (Greaves N, October, 2018, personal communication). Before the introduction of these services, palliative care was offered only on an ad-hoc basis by a few individual practitioners. The ability of civil society organisations to sustain these palliative care services on the island through collective organised action, despite a lack of government involvement, is considered a major achievement in Barbados. Nonetheless, even in the face of these new services, there is still a large, unmet need for palliative care in Barbados, with a 2012 analysis showing that approximately 1700 people in Barbados would benefit from palliative care in their last year of life (unpublished). Although palliative care is included in the country's draft cancer plan, no government policies, monitoring, or evaluation of palliative services currently exist.

A second initiative in the Caribbean to expand home-based and community-based hospice and palliative care services is the Cayman Hospice Care (CHC) programme (now called Jasmine), a community palliative care and hospice service that has been in operation for over 20 years, and which was recently expanded in 2018 through a public-private partnership. Founded in 1996, in response to an unmet need to provide end-of-life care at home, the CHC is a programme specifically designed for patients of any age who are living with a serious illness or injury and have complex care needs. Care is provided principally in patients' homes by a core clinical team of seven health-care professionals, which includes a physician, registered nurses, and certified caregivers.

Volunteers also have an important role in care delivery. The CHC programme is a small but essential service for the island's population of roughly 60 000 people, providing care to approximately 65 patients a year (unpublished). 50% of these patients have cancer and 50% have other NCDs. Patients are on the service for an average of 90 days (unpublished). CHC's care is free to patients and their families, even though the Cayman Islands' Ministry of Health contributes only 16% of the overall operating budget (unpublished). The remaining 84% of the programme's budget is raised from the country's small, but affluent, business community through fund- raising events and private contributions.

Over the past 20 years, CHC has raised its profile to become a well respected organisation providing high-quality hospice care for people in their own homes. This could not have been possible without enormous financial support from the Cayman Islands' private sector. This is evidenced by the private sector's support in financing a US$2·5 million purpose-built hospice,

which is currently under construction. CHC notes that the key to its continued success is providing continuing education for the communities they serve and delivering a high-quality, specialised care service that becomes a powerful self-advocacy tool in this small sland nation, and which helps them advocate for continued financial support and for increasing acceptance of palliative and hospice care by the general public. CHC not only provides hospice services, but it also has become a leader in developing national policies that support the delivery of high-quality palliative care services. One persistent difficulty encountered by the programme, for example, has been the absence of a legal framework in the Cayman Islands that recognises advance directives or living wills. To the best of our knowledge, this lack of legal guidance is true of many other countries and territories throughout the Caribbean. The CHC team has engaged the Cayman Islands' Government in addressing this issue, and provision is currently being made to draft a health-care law (which is currently with cabinet for gazetting) that will respect the binding nature of an advanced directive (McLean F, April, 2019, personal communication).

Improving opioid availability and use in Jamaica

Central to advanced cancer management is having appropriate medication for pain control. By contrast to the community care provision seen in Barbados and the Cayman Islands, palliative care services in Jamaica are primarily hospital-based. Analgesics for the management of cancer pain became available in the island in the early 1970s and ranged from older opioid formulations, such as pentazocine and dextropropoxyphene, to the Brompton cocktail, consisting of syrup, ethyl alcohol, morphine, and cocaine.[50] Sustained release morphine became available in the mid-1980s, but most physicians in Jamaica (and in the Caribbean) are uncomfortable with prescribing strong opioid preparations, including morphine, because they are afraid of creating opioid addiction among their patients. Immediate release morphine, a WHO essential medicine[51] for the treatment of cancer pain, has been available in the country since 1996, but only through a cumbersome, in-hospital manufacturing process. Historically, this medicine was only available in four of the 24 public-sector hospital pharmacies. Even within these four hospitals, opioids were frequently out of stock, and management of severe pain was a substantial problem (unpublished).

In 2008, a physician and pharmacist team from Jamaica were awarded an International Pain Policy Fellowship,[53] a 4-year education and mentoring initiative focused on supporting recipients in improving the access and availability of opioid medicines in Jamaica. The Fellowship highlighted three principal areas of difficulty with opioid access in Jamaica. First, a pervasive so-called opiophobia (fear of prescribing, administering, and dispensing opioids) is present among health-care professionals in the region. Second, there are few opportunities for training in pain management and palliative care. Third, there are problems with the island's opioid distribution system because only a pharmacist, physician, or registered nurse can collect controlled medicines from the central pharmacy based in Kingtson, Jamaica. Therefore, a pharmacist who works alone in a rural area might have to close their pharmacy for the day and drive to Kingston in their own personal vehicle to collect opioid supplies for the pharmacy. Through visits to each of Jamaica's 24 public hospitals, meetings with multiple stakeholders, assessment surveys, and guideline and policy development, fellows were able to raise awareness of the crucial need for palliative care and pain relief for patients with cancer in Jamaica. A principal achievement was to facilitate the importation of immediate release morphine tablets in both public and private sectors, reducing the need for older compounding technology and making this medicine more widely available. In Jamaica, morphine consumption per capita has risen steadily, but total opioid consumption has risen sharply over the past few years (figure 2).[52]

Securing availability of guideline recommended opioids for cancer treatment is only helpful to the extent that providers are willing to prescribe such medications. Due to the scarcity of training in palliative medicine among most clinicians trained in the Caribbean, many physicians are uncomfortable with prescribing opioids. In response to this urgent need to develop palliative care services in the region, the Jamaica Cancer Care and Research Institute (JACCRI), a non-profit organisation affiliated with The University of the West Indies, began a palliative care training programme open to providers throughout the region. JACCRI has assessed providers' baseline knowledge of palliative medicine and delivered two 2-week-long training programmes in palliative medicine, one in 2017, and the other in 2018. Each course attracted more than 80 different clinicians from six different countries in the Caribbean. Faculty for these regional palliative care programmes included palliative care leaders in Jamaica, Jamaica's only certified hospital chaplain, and collaborating faculty from Massachusetts General Hospital and Harvard Medical School, Boston, MA, USA.

JACCRI has been funded through pilot grants from the Harvard/MGH Center on Genomics, Vulnerable Populations, and Health Disparities; the US National Cancer Institute; individual philanthropy; and substantial support from Jamaica's private sector. The training programmes would have been impossible without the support of Jamaican business leaders. Plans are underway to develop a diploma programme in palliative medicine through The University of the West Indies, as well as work with Jamaica's Ministry of Health to develop positions for palliative care experts within regional hospitals and health centres to provide a career track for those wishing to specialise in palliative medicine.

For more on the **JACCRI** see https://cgvh.harvard.edu/JACCRI-Mission

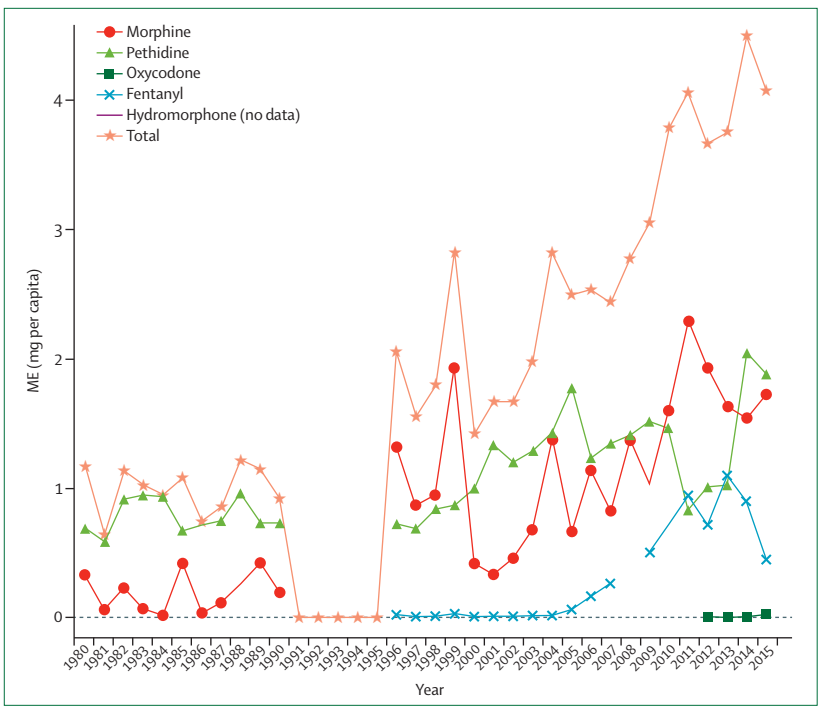

Figure 2: **Opioid consumption in Jamaica from 1980 to 2015**
ME=morphine equivalence. Reproduced from the Pain and Policy Studies Group[53] by permission of University of Wisconsin and WHO Collaborating Center.

Features of successful capacity-building initiatives for the Caribbean

Among CARICOM nations and small island nations discussed in this Series paper, many have substantial resource constraints that limit access to guideline recommended treatment for patients with cancer. Major barriers include insufficient funding from the public sector to ensure access to care, inability to provide quality treatment outside urban areas, inadequate availability of cancer specialists on the island, scarcity of necessary medical equipment and medications needed to provide optimal care, and lack of training among clinicians treating patients with cancer in some crucial areas of cancer care. In examining regional initiatives aimed at improving cancer care and treatment in the Caribbean, those that have had a positive capacity-building effect in the Caribbean share several features, which appear to be hallmarks of successful interventions for the region.

Public–private partnerships at the local level

For more on the **Caribbean Cancer Research Initiative** see https://www.ccrinitiative.com

For more on the **African-Caribbean Cancer Consortium** see http://www.ac3online.org

All effective cancer control interventions within Caribbean small island nations have required partnerships between the public and private sectors. Due to historical gaps in critical health-care resources available in the public sector, leaders in the private sector are routinely relied upon to contribute in substantial ways, and it is not uncommon for the business community to have an indispensable philanthropic role in financing health-care services and other initiatives. Philanthropic support and public–private partnerships have helped build the essential infrastructure needed to extend access to care for many more patients with cancer, buy new medical equipment, support provider training, train health workers in health information technology, and support opportunities for mentorship and networking both regionally and internationally, thus helping health-care professionals gain essential expertise for the benefit of their country and peoples. All initiatives identified in this Series paper reflect public–private partnerships in which NGOs have supported local governments in developing cancer surveillance systems, building needed facilities and equipment, developing a trained workforce, and increasing access to timely and appropriate cancer treatment strategies.

Establishing partnerships with developed countries to build regional capacity

The flow of information, expertise, and financial resources from developed countries such as the USA and Canada continues to make essential contributions towards meeting basic population health needs in virtually all Caribbean small island nations. Even modest investments by academic institutions, non-profit organisations, and government programmes have been responsible for dramatic improvements in cancer control throughout the region by providing essential financial and clinical support. An important component of successful partnerships with developed countries in the Caribbean has been the identification of local leaders on the ground with whom the international partners have partnered to perform initial needs assessments and to identify knowledge gaps. These partnerships have then deferred to local leaders to set priorities for research, education, training, clinical consultations, information systems, and interventions. Within those collaborations that have been successful, the knowledge and expertise within small island nations have not only been acknowledged by international partners, but this acknowledgment has also been crucial for successful capacity building for the region. Such collaborative partnerships have included innovative research that has been aimed at better understanding the determinants of cancer in the Caribbean and the drivers of high incidence or mortality rates for certain cancers in the region. This drive has generated new knowledge that has been useful for tailoring successful cancer interventions to local contexts. Several successful partnerships have already been established in the region, including CAOH, JACCRI, AHOPCA, SCI, Caribbean Cancer Research Initiative, and the African-Caribbean Cancer Consortium.

Strengthening regional collaborations to share clinical expertise and resources

Regional collaborations can have a substantial effect on advancing cancer care, research, and education. Early stories of success from the IARC Caribbean Cancer Registry Hub, AHOPCA, and SCI, highlight the power of

sharing resources and expertise more broadly within the Caribbean region to make meaningful improvements across the cancer control continuum. Such collaborations will be a key part of developing a sustainable, regional capacity for cancer control that allows local providers and practitioners to be increasingly less reliant on the flow of resources from other nations. The development of regional training centres of excellence and the increased use of online and telemedicine platforms can help to grow local expertise. Pre-existing academic institutions such as The University of the West Indies are primed to provide high-level postgraduate education in all aspects of cancer control, and support from local and regional governments will be essential for maintaining their viability and sustainability over time.

Adapting best practices to local contexts and resources

Successful efforts towards cancer control in the Caribbean have emphasised the need for adaptation to local culture, politics, and resource constraints. Tailoring established NCCN clinical guidelines into resource-stratified guidelines for the Caribbean shows that positive albeit incremental change is happening. The process of tailoring any cancer control intervention to local cultural preferences, knowledge, and resources requires a learning process on the part of the collaborators, and a sustained commitment to learning from their small island nations or LMIC counterparts. Both of these steps will be essential to improving cancer care over an extended period of time in the Caribbean.

Conclusion

Looking to the future, it seems clear that both horizontal collaboration among island nations in the region and vertical collaboration between small island nations and academic and policy collaborators from developed countries will be important contributions for optimising resources in the region. Horizontal collaboration and pooling of resources and expertise is not only efficient but is also essential for delivering high-quality cancer control services, both for quality service delivery and capacity building. Vertical collaboration continues to be valuable to small island nations to aid development of academic faculties and the research capacity needed to identify priorities and evaluate the effectiveness of cancer control efforts. Training in new platforms and methods for detection and treatment, informatics, implementation science, and transdisciplinary research more broadly is greatly needed throughout the region. Horizontal and vertical collaboration are both important to improving cancer control in the Caribbean and should be fostered in mutually sustainable ways.

Developing creative and sustainable models for financing cancer care in the Caribbean remains a central concern. Offering a full range of services through the public sector will have little affect if these services are underfunded and are thus unable to meet demand and provide care for all patients. Collaboration at the regional level to identify innovative models of cancer care financing and delivery care models that seek to strengthen services throughout the region and take advantage of shared purchasing could go a long way to improving the availability of services on the ground. Organisations such as PAHO, CARICOM, and CARPHA will be key to identifying and implementing optimal strategies.

Last, most aspects of an effective cancer control programme depend on information. Priorities for cancer prevention and control cannot be identified nor can the effectiveness of interventions be evaluated without access to high-quality data from cancer registries. However, developing high-quality cancer registries is similarly dependent upon robust health information technology, especially electronic health records, which have been shown to have potential to improve efficiency and effectiveness of health-care providers.[53,54] In LMICs, multiple financial, political, and infrastructural barriers hinder the widespread implementation of health information technology.[55] Although Jamaica, The Bahamas, and Trinidad and Tobago have plans to implement an electronic health record system nationwide, time to implementation of the electronic health system remains unclear. In Barbados, electronic health records are used in primary care, but are not yet available in public hospitals. Few initiatives would have a more profound effect on cancer control in the Caribbean than would establishing compatible electronic health record systems throughout the region and promoting reliable health information exchange systems to better coordinate cancer care and prevention throughout the entire Caribbean region.

Looking ahead, we see many opportunities to advance cancer care in Caribbean small island nations. Although many challenges remain, the surge of exciting and effective initiatives that have taken place thus far throughout the Caribbean and across the cancer control continuum provide hope for the future.

Search strategy and selection criteria

We solicited information from key informants throughout the Caribbean to identify and describe innovative strategies addressing various aspects of the cancer control continuum in their countries. We then searched PubMed and publicly available reports from the Caribbean Ministries of Health, Pan American Health Organization and WHO, GLOBOCAN, and the World Bank for supporting literature published between May 16, 2006, and July 29, 2019, to provide further context where available. Only articles in the English language were considered. No systematic search terms were used.

Contributors

DS was the lead author and participated in writing the introduction and conclusion recommendations, wrote the sections on palliative care and

improving access to opioids, and reviewed and edited the Series paper. AES worked with DS to develop the overall structure of the paper; contributed to the writing of several sections, including the introduction and conclusion; and edited the paper. MAA conducted literature reviews related to the paper, contributed to the writing and editing of several sections of the manuscript, and created tables 1 and 2. FB led the section on cancer registries, with input from GA-B, LM, and GT-L. BOA led the section on clinical treatment guidelines, with input from CD and MN. SG led the section on paediatric cancer, with input from CB, TG, WGG, OO, and CSQ-B. NG, FM, and VH contributed to the writing of the section on palliative care. All coauthors reviewed and approved the final submitted version.

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