

# SCI

## SickKids-Caribbean Initiative

Enhancing Capacity for Care in  
Paediatric Cancer and Blood Disorders

# Reflections on the SickKids-Caribbean Initiative: Advocacy and External Engagement



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# Abstract

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In addressing worldwide health inequalities, the development of global health partnerships that integrate advocacy efforts and external engagement can play a key role. This technical paper describes the activities and lessons related to advocacy across several diverse groups, including healthcare professional societies, international agencies, decision makers, and civil society, in the context of the SickKids-Caribbean Initiative (SCI). With the aim of improving the outcomes and quality of life for children with cancer and blood disorders in the Caribbean, SCI helped to foster and formalize connections locally, nationally, and internationally. Multiple activities played an important role in promoting advocacy, ranging from professional society engagement, implementing advocacy-focused projects in a clinical setting, organizing workshops, and fostering the development of a regional community of advocates.

## Introduction

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Advocacy is a critical component of the global betterment of health. Engaging diverse actors within society, from advocates to decision- and policy-makers, is a core component of advocacy. It allows for many to lend their respective expertise to the effort to reduce health inequities and guide policy development.

The development of global health partnerships is a recognized way to address health inequities worldwide. Fostering relationships and partnership programming between resource-constrained and resource-abundant countries has a history of improved change around the improvement and delivery of essential health services (WHO 2016). One of the key pillars in addressing these health inequities is advocacy. Advocacy is therefore an important strategy for using evidence to promote awareness which guides policy. This can further foster improvement in health equity (Farrer et al 2015).

Successful healthcare partnerships require clear goals set out in the context of the recipient country's setting, with a multifaceted approach through funding, engagement, and technical assistance (Caines et al 2004). Advocacy directed at all stakeholders at all levels to achieve the common goals of the partnership is paramount to the success of global health partnerships.

This technical paper reflects on the role of advocacy and external engagement of diverse stakeholders in fostering a successful partnership between six English-speaking Caribbean countries and the Hospital for Sick Children, formally known as the SickKids-Caribbean Initiative (SCI), to improve the outcomes for children with cancer and blood disorders in the Caribbean.

# Overview of SCI and Program Components

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## SickKids-Caribbean Initiative Overview

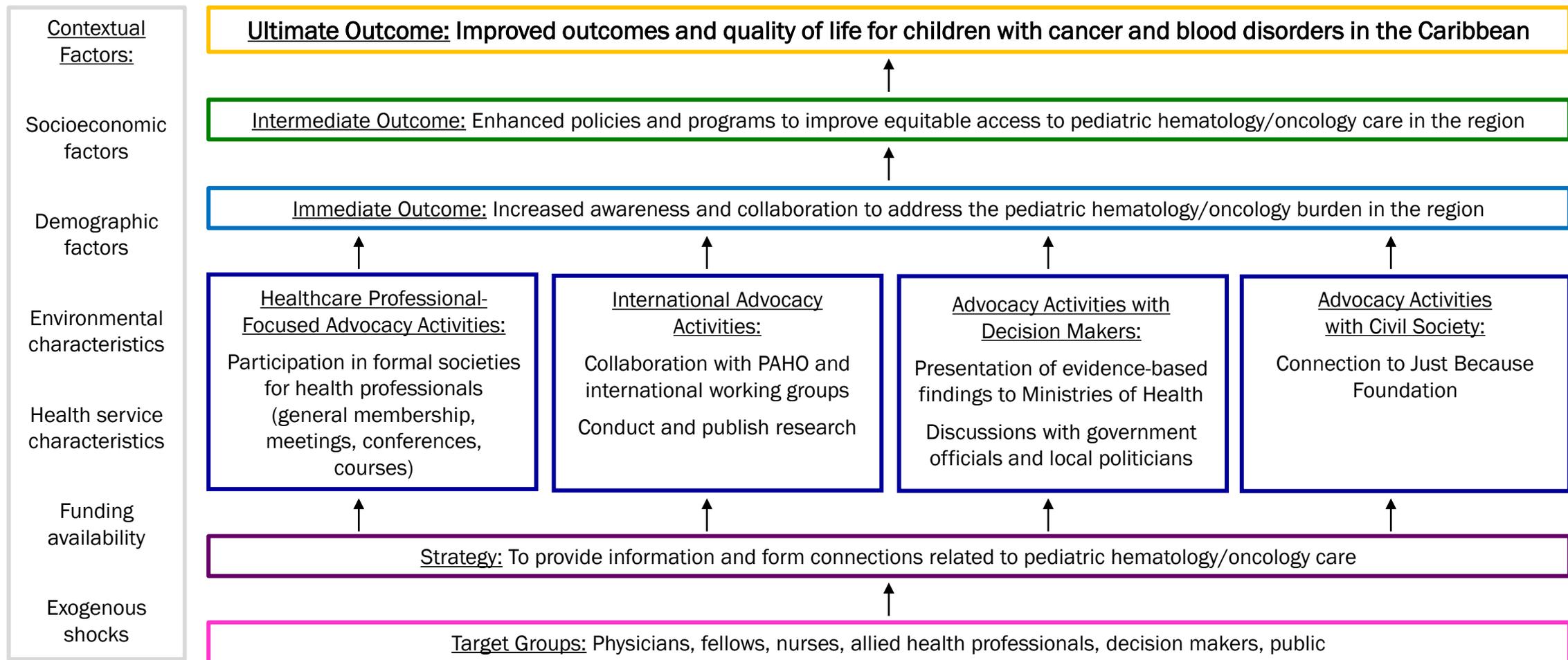
Formally launched in 2013, SCI is an innovative nine-year program in six Caribbean countries, focused on activities to improve the capacity of local health care professionals to diagnose and treat children with cancer and blood disorders. As a non-profit partnership between The Hospital for Sick Children (SickKids) in Toronto, Canada, the University of the West Indies (The UWI), Ministries of Health, and hospitals at seven sites in the six Caribbean countries (Barbados, The Bahamas, Jamaica, St. Lucia, St. Vincent and the Grenadines, and Trinidad and Tobago), key outcomes of the partnership have included increasing the number of physicians and nurses in the region with specialized skills around pediatric hematology and oncology care; improving health care professionals' ability to diagnose, treat, and manage pediatric hematology and oncology patients; facilitating regional, international, and inter-professional collaborations around pediatric hematology/oncology; and developing a system of real-time oncology data collection linked to REDCap pediatric oncology databases.

## Forms of Advocacy and External Engagement

Several forms of advocacy and external engagement have been incorporated within SCI internally and externally, with the aim of improving the health and quality of life of children with cancer and blood disorders in the Caribbean (**Figure 1**). These have spanned from engaging with other allied health professionals in the field to partnerships with international agencies, advocating to government representatives, and liaising with public interest groups.

## Healthcare Professional Societies

Within SCI, there has been an emphasis on fostering linkages with other allied health professionals around the discipline of pediatric hematology/oncology. For various individuals, this has included the support of formal memberships and/or engagement with the American Society of Hematology (ASH) and Children's International Consortium for Acute Leukemia Initiative (C-ICAL; **Box 1**), American Society for Pediatric Hematology/Oncology (ASPHO), Caribbean Institute for Health Research (CAIHR), Caribbean Network of Researchers on Sickle Cell Disease and Thalassemia (CAREST), Caribbean Nurses Organization, International Society of Pediatric Oncology (SIOP), and the Global Sickle Cell Disease Network (GSCDN). Through these linkages, such individuals have been able to make valuable connections with others in their field, as well as benefit from meetings, conferences, and courses where SCI-related efforts could be shared formally and informally. Importantly, this has contributed to building the international advocacy agenda of these societies, particularly in relation to pediatric hematology/oncology in the Caribbean. These alliances with prominent international societies, such as ASH, have also been used to advance the advocacy agenda with members of the pharmaceutical industry to improve drug access for some newer agents (e.g., asparaginase) that are not readily available in the Caribbean region.



**Figure 1.** Framework of activities and outcomes within SCI related to advocacy and external engagement

### **Box 1: Children’s International Consortium for Acute Leukemia Initiative (C-ICAL)**

As a formal global initiative of ASH, in partnership with SCI, C-ICAL aims to improve the outcomes and cure rates among children and adolescents with acute lymphoblastic leukemia (ALL). Four SCI countries are engaged in C-ICAL. These include The Bahamas, Barbados, Jamaica, and Trinidad and Tobago. C-ICAL involves a standardized ALL protocol, adapted to the local Caribbean resource context, together with opportunity for the Caribbean-based physicians to review specific cases with international leukemia experts. Through the intervention of some of those international leukemia experts, C-ICAL has also led to improvements in drug access (e.g. asparaginase) necessary to carry out the ALL protocol. The long-term goal of C-ICAL is to enroll 100 cases and report on patient outcomes 2-3 years post-recruitment.

### **International Agencies**

From an international perspective, some of the Caribbean physician leads within SCI were invited to join the Pan American Health Organization (PAHO) Childhood Cancer Working Group for Latin America and the Caribbean. In this role, they have been able to participate in joint priority setting and action planning activities, as the purpose of the group is to develop health policies and programs to improve equitable access to care for children with cancer in Latin America and Caribbean countries.

### **Decision Makers**

Engaging with decision makers, such as Ministries of Health, government officials, and other politicians has been an important component of advocacy within SCI. The buy-in from the Ministries of Health for the various countries involved was a crucial step in supporting SCI. In some instances, this engagement was formalized via the signing of memoranda of understanding. Government engagement has been particularly helpful around issues such as newborn screening for sickle cell disease (SCD) and advocating for access to the drug hydroxyurea for use in children with SCD. Another example of engagement with decision makers has been SCI’s outreach to governmental-linked agencies, such as the Caribbean Community and Common Market (CARICOM) and PAHO, to address the drug access and availability issues that impact on outcomes for children with cancer and blood disorders in the Caribbean region. An additional key stakeholder linking the partner countries with the government entities was The UWI. The relationship between The UWI and SCI was formalized from inception of the project and proved to be an important advocacy alliance (Manley-Kucey et al 2023).

## Civil Society

Community-based groups and non-governmental organizations (NGOs) can play an important role in filling a gap in patient care not covered by the government or healthcare services (e.g., finding accommodations, providing emotional support to families). As such, civil society groups and foundations have a role in promoting awareness of the burden of pediatric hematological and oncological issues and advocating for changes in evidence-based diagnosis and care. Engaging with these groups, such as the Just Because Foundation (JBF; <https://thejustbecausefoundation.com>) in Trinidad and Tobago and the Healthy Caribbean Coalition (<https://www.healthycaribbean.org>), to promote awareness and education has helped with public-facing advocacy within SCI.

## Methods

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To inform this technical paper, we reviewed past internal and external SCI reports, including the independently prepared midterm and final evaluation (Rudiack-Gould and McGuire 2016; Salehi 2020). The four themes were identified from this review and approved by the SCI Research, Policy and Advocacy Working Group. All co-authors were asked to complete a survey to ascertain key activities and provide feedback on each of the four themes related to the major successes, challenges, and areas for further improvement. Anonymized responses were reviewed and summarized. There were also follow up conversations with specific co-authors to gather additional details around certain elements.

## Themes

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### Communities versus Silos

While there has always been a history of advocacy around pediatric hematology/oncology among the Caribbean partners, the formation of SCI helped to formalize efforts and foster additional connections. Healthcare professionals were able to connect with one another for a unified cause locally, as well as develop collaborations with others in the field internationally. This has come full circle, as the international linkages have been leveraged to lend support to local advocacy efforts by providing resources.

Prior to the SCI partnership, all of the participating SCI Caribbean countries were involved in some form of hematology/oncology-related advocacy to varying degrees of success. Advocacy-related activities were conducted largely independently at many levels, either by directly funding individual patient care or by investing in improving cancer centers. Advocacy was used by healthcare professionals to lobby healthcare institutions to improve available services and assist with payment for investigations

not available in country. Also, non-medical service organizations (e.g., Royal Bank of Canada (RBC)'s RBC/RBTT Caribbean Children's Cancer Fund [<http://www.rbcroyalbank.com/caribbean/give-hope-save-lives/refer-a-child.html>]) have assisted financially with the treatment of children with cancer in the region. Patient-based advocacy also included formal and informal support groups or collaborations with NGOs.

With the generation of the SCI partnership, the importance of advocacy in achieving the overall goal of improving outcomes for children with cancer and blood disorders in the Caribbean region was recognized as a core principle. Early in the history of SCI, a working group that prioritized research, scholarly activity, and advocacy was formed. Part of the remit of this working group was to investigate ways that advocacy could be developed to improve the outcomes for children with cancer and blood disorders in the Caribbean. Through the SCI partnership, individual advocates in each island were strengthened in many different ways.

Advocacy training was embedded in the curriculum of the pediatric hematology/oncology nursing diploma program developed and launched by SCI and The UWI School of Nursing. This training included a 'change project' related to advocacy, wherein nurses were to design and implement a project in their home territory that would be impactful.

The two Caribbean co-leads of SCI were also supported by SCI to attend the 2016 Union of International Cancer Control's master course in advocacy for improved cancer control. The co-leads then shared what they learned via a workshop for the broader community of practice within SCI, and for all operational NGOs in the SCI participating countries. The workshop served as an excellent way for all involved to share advocacy activities being undertaken and advocacy strategies being employed.

For each country, it was important to identify key goals for any advocacy activity. Often these goals or approaches were different for the various advocates in each country, thus addressing the advocacy activity in each silo to strengthen the efforts was an important focus. Bringing the inter-professional groups (e.g., nurses, doctors, NGOs) to the table to create one voice was a powerful impetus for moving the narrative forward. This was indeed an important initiative as it has fostered inter-professional engagement and commitment to common advocacy goals targeting stakeholders at different levels.

The organization of the advocacy activities in each country was important. Fortunately, SCI annual work planning meetings offered a regular opportunity to align advocacy themes and strategies. Through the recognition of common themes, such as newborn screening for SCD or drug availability, building a regional Caribbean advocacy agenda which could be far more powerful was fostered. After identifying common themes, the next step in advocacy planning involved gathering data to support the advocacy activity.

This step was crucial to provide an informed and holistic approach to the advocacy dialogue. Valuable sources of supportive data including SCI-supported local pediatric oncology databases at each SCI Caribbean partner hospital and the drug access and availability study conducted across the partnership countries (Gibson et al 2018; Boateng et al 2021; Browne-Farmer et al 2023).

As a community, the SCI partners engaged with international societies such as ASH, SIOP, and World Federation of Hemophilia (WFH). At the international conferences held by these societies, the SCI partnership was able to share local data highlighting the needs of the Caribbean region with a broad, international audience. This association with recognized societies, such as ASH and WFH, led to very powerful advocacy campaigns championing access to specialized test and drug availability. This had a role in drawing the attention of international agencies, such as PAHO. SCI fostered both an inter-professional body, as well as regional discussion/support amongst NGOs in the region. This regionally coordinated approach to advocacy was paramount for the success of the SCI partnership.

Another recent initiative to break down silos has been the creation of the Caribbean Sickle Cell Disease Scorecard (<https://www.caribbeanscdscorecard.org/>), which aims to provide data about the status SCD diagnosis, care, research, advocacy, training and education, collaborations, and governance across the Caribbean region. These data will be useful for those living with SCD and their families, clinicians, advocates, researchers, and public health practitioners. Through collaboration between the founding partners, the Caribbean Institute for Health Research Sickle Cell Unit, SCI, and CAREST, the hope is that it will provide a basis for further collaboration and development of SCD programs across the Caribbean region.

## Building Local Capacity versus Parachuting in

The challenge of the SCI partnership from the very inception revolved around engagement of six very different Caribbean countries at very different stages of development of care and outcomes for children with cancer and blood disorders. From early on, dialogue was centered around the needs of each of the participating countries and what resources were available. A good example of this is the nursing change project described in Theme 1, which focused on the immediate needs unique to the corresponding partner country. Finding commonalities across the region was also an important step. This was combined with continued support for each island to overcome their unique challenges by sharing experiences of how these challenges were addressed in other settings. To this end, one of the prominent local NGOs, The JBF, through SCI partnered with an international advocacy expert, Ritu Sharma from Radiant Advocacy, to create an advocacy workshop for fifteen experienced advocates working in childhood cancer and blood disorders in the Caribbean region. The workshop focused on empowering participants to formalize a regional pediatric cancer and blood disorders network.

The objectives of the workshop were based on the participants' desire to:

1. Gain new advocacy knowledge and tools for a more systematic, effective, and sustainable approach to their advocacy activities;
2. Learn from each other's current techniques and approaches to advocacy; and
3. Create a network of Caribbean pediatric cancer and blood disorders advocates to collaborate and support each other.

Having now fostered these strong inter-professional advocacy bodies within the Caribbean region, the next step was to generate the common advocacy themes that would be most effective at achieving the common goal of the SCI partnership, improving the outcomes for children with cancer and blood disorders in the region. At a later SCI annual work planning meeting, the SCI regional partners were provided with space to meet independently of SickKids partners and with an independent moderator not involved in the partnership. Caribbean partners could then engage in open discussions and reach consensus around the advocacy agenda prior to sharing it with SickKids. The joint discussions with the independent moderator also supported regional ownership, as it created an environment where regional partners did not feel intimidated and were thus more empowered to create their own agenda. Having generated the key themes for the advocacy agenda, the SickKids partners' engagement was aimed at lending additional expertise to achieve the regional goals.

## Strengthening versus Supporting Health Systems

SickKids has had a long and successful history in advocacy, hence the partnership provided invaluable support in moving the advocacy agenda for children with cancer and blood disorders forward in the Caribbean region. Having identified both local and regional advocacy themes, the partnership put in place numerous support measures to ensure that advocacy activity had the maximal effect. Examples where SCI activities initially offered support and then were leveraged to advocate for more sustainable and strengthened healthcare systems include:

- Specialized diagnostic services  
Access to specialized diagnostic services not normally available within the SCI partner countries was one of the key areas in which SickKids played a more supportive role in Phase 1 of SCI. Through advocacy activities in the region involving governments and NGOs, local diagnostic services were developed and enhanced in selected countries (e.g., flow cytometry services in Jamaica), as further described by Thame et al (2023).
- Nursing education  
Nursing education is key to strengthen the health systems and was achieved in the context of SCI by providing scholarships for nurses in participating

countries to access specialist training, as further described by Reece-Mills et al (2023). Nurses returned to their host countries with a skill set to enhance the management of children with cancer and blood disorders, and the training curriculum contained an advocacy component (change project), highlighting the importance of advocacy at all levels to effect change.

From a funding perspective, SCI's funding partner, SickKids Foundation, engaged local partners in fundraising and advocacy activities. This led to a true feeling of local ownership and helped tailor messaging to specific audiences in each country while also disseminating overarching messages that were applicable to the region as a whole.

The initial focus during Phase 1 (2013-2018) of the SCI partnership was mainly capacity building and support; however, this shifted in Phase 2 (2018-2022) to sustainability. The initial Research, Scholarly and Advocacy Working Group morphed into a Research, Policy and Advocacy Working Group, wherein the research generated could be used to instigate policy changes through advocacy and external engagement. With regards to drug access, research about essential medicines for improving outcomes for children with cancer and blood disorders, coupled with collaboration to inform the advocacy agenda, was a powerful tool. Partnership with SickKids' Policy and Economics Research in Childhood Cancer led to collaborative research highlighting the extent of the challenges SCI partner countries faced in accessing essential medicines (Boateng et al 2021). Presentation of essential data at international conferences and publication in academic journals has facilitated discussions between international agencies and regional governments to find solutions to this challenge. This two-pronged approach of sharing supportive expertise and strengthening health systems has created a more robust and sustainable advocacy environment in each SCI partner country and regionally.

## Optimized versus Routine Practices

Successful and effective advocacy requires a clear message and tailored delivery. Prior to SCI, each local advocacy group pursued their individual agenda, and often the method of delivery chosen by the individual advocates/groups did not facilitate the desired outcome. SCI created an opportunity to allow advocacy at the local- and regional-level to be more effective, by teaching advocates how to develop clearer agendas and use resources more effectively. By creating a regional community of advocates sharing their experiences and reflecting on the effectiveness of their advocacy activities, each participating country was better able to define their advocacy agendas and develop strategies to achieve the desired goals in their local context. This transmission of contextual knowledge created a readily adaptable advocacy approach, effective in both the local and regional context. Collaboration with local, regional, and international groups further enhanced the effectiveness of these approaches.

# Discussion

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Advocacy is one of the key pillars in addressing inequalities in health. The SCI partnership recognized the importance of advocacy and engaging external stakeholders in maximizing the outcomes for children with cancer and blood disorders in the Caribbean region. The partnership successfully raised awareness by creating a clear and unified agenda that was articulated consistently locally and regionally, and offering opportunities for advocacy skill-set expansion. Development of a clear advocacy agenda was one of the earliest and most important achievements of the project. This fostered local ownership and a strong sense of 'buy in' from the local partners. Although there was a strong local identity, the recognition of common advocacy themes was also fundamental for creating a strong Caribbean region-centric agenda that appealed to international stakeholders.

The SCI partnership recognized that for advocacy to be successful, data to inform and guide policy were lacking. Gathering the necessary data, such as patient volumes, outcomes, and challenges to optimal care, allowed the advocacy narrative to consequently move forward.

A balance of support and strengthening of existing systems created a robust framework to rapidly advance the advocacy activity. Partnering with an institution with an established, internationally respected, high-profile reputation, such as SickKids, enhanced the credibility of the collaboration. This was carefully balanced with the need to rapidly build advocacy capacity on multiple levels (e.g., individuals, healthcare professionals, NGOs) in the local and regional environment.

Development of clearer unified themes with better advocacy messaging, coupled with the SCI partnership, opened the doors for further partnerships with more international agencies. Through joint advocacy for a common goal of health equity, collaborations with ASH, PAHO, SIOP, and WFH have come to the fore.

A remaining challenge for the Caribbean region, with so much diversity in population demographics, social differences, and resources, is determining how to create unified solutions to challenges that affect the outcomes for children with cancer and blood disorders in the region. Moving forward, SCI Caribbean partners, and all those interested in improving pediatric health outcomes in the region, must continue to invest more in research to understand the barriers and enablers to reaching that goal.

This SCI partnership has certainly been a success story. It has allowed each of the countries involved to be able to articulate its advocacy message loudly, clearly, and confidently. The outcome for children with cancer and blood disorders in the Caribbean region must, can, and will be better.

# Contributions

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CB prepared the first draft of the manuscript, with assistance from JBB and CA. JBB designed the survey, and all remaining authors provided input on the key activities and themes related to advocacy and external engagement within SCI via the survey. All authors read, provided additional feedback, and approved the final draft.

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