

# The SickKids Caribbean Initiative to improve care for children with cancer and blood disorders

Michelle Reece-Mills<sup>1</sup> and Jo-Anna B. Baxter<sup>2</sup>

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## ABSTRACT

To improve pediatric hematology and oncology outcomes, there is a recognized potential for partnerships between low- and high-resource institutions within health care systems. The SickKids Caribbean Initiative is a partnership between health care professionals at the Hospital for Sick Children in Toronto, Canada, and seven Caribbean institutions across six countries (Bahamas, Barbados, Jamaica, Saint Lucia, Saint Vincent and the Grenadines, and Trinidad and Tobago). The primary aim of the SickKids Caribbean Initiative has been to improve the outcomes and the quality of life of children in the Caribbean aged <18 years who have cancer and blood disorders. This article describes five key activities undertaken within the SickKids Caribbean Initiative, including providing education and training, assisting with case consultations and diagnostic services, developing local oncology databases, engaging in advocacy and ensuring stakeholder engagement, and coordinating administration and project management.

## Keywords

Caribbean Region; medical oncology; oncology nursing; hematology; anemia, sickle cell; pediatrics; education, medical; database; health advocacy.

## PEDIATRIC HEMATOLOGY AND ONCOLOGY IN THE CARIBBEAN

Substantial barriers to accessing health services and testing are faced by large portions of the population in the Caribbean. These can range from a lack of specialized medical training and the correspondingly trained health care professionals to the lack of adequate infrastructure and resources (e.g. diagnostic tests, essential medicines, systems for monitoring and tracking cases). With respect to pediatric hematology and oncology, the prognoses of children in the Caribbean are more comparable to those of children in low-resource settings, although the islands that make up the Caribbean are mostly upper-middle- and high-income countries, based on their gross domestic product. Using pediatric acute lymphoblastic leukemia as an example, Ward et al. (1) estimated the 5-year net survival rate to be 89.8% in North America, 61.4% in Latin American and the Caribbean,

52.6% in Asia and 22.4% in Africa. Among the six countries within the SickKids Caribbean Initiative (SCI) partnership (Bahamas, Barbados, Jamaica, Saint Lucia, Saint Vincent and the Grenadines, and Trinidad and Tobago), we found the 2-year event-free survival rate for pediatric acute lymphoblastic leukemia to be 62.1%, although this was higher than for other forms of cancer (2).

This risk of poor clinical outcomes is attributable to limited investment in pediatric oncology care, which has led to few advancements in the ability to diagnose, treat and manage health outcomes among pediatric patients, particularly relative to high-resource settings. To improve pediatric hematology and oncology outcomes, there is a recognized potential for partnerships between low- and high-resource institutions within health care systems that are grounded in improving the quality of care, supporting local knowledge through education and strengthening infrastructure.

<sup>1</sup> Department of Child and Adolescent Health, Faculty of Medical Sciences, University of the West Indies, Kingston, Jamaica ✉ Michelle Reece-Mills, [michelle.reece02@uwimona.edu.jm](mailto:michelle.reece02@uwimona.edu.jm)

<sup>2</sup> Centre for Global Child Health, The Hospital for Sick Children, Toronto, Canada

## THE SICKKIDS CARIBBEAN INITIATIVE

In 2013, health care professionals at The Hospital for Sick Children (SickKids) in Toronto, Canada, partnered with seven Caribbean institutions across six countries. Referred to as the SickKids Caribbean Initiative (SCI), the primary aim of SCI has been to improve the outcomes and quality of life of children aged <18 years who have cancer and blood disorders by enhancing expertise in pediatric hematology and oncology, and access to diagnostic services.

What began as an informal relationship between physicians at SickKids in Toronto who are members of the Caribbean diaspora and their clinical and academic colleagues at institutions in the English-speaking Caribbean (e.g. assistance with case consults, information-sharing with respect to humanitarian initiatives) led to a needs assessment and stakeholder engagement activities during 2009–2010 to identify core partners, institutions, governments and donors. The preliminary selection of participant countries was based on these pre-existing relationships, as well as the established relationships that the SickKids Foundation had with donors specifically interested in supporting work in pediatric cancer and blood disorders in the Caribbean. These two factors (i.e. existing clinical and academic links, and funding), together with an awareness of need, culminated in a strategy and planning meeting. In 2010, clinical leads met in Barbados with SickKids clinical, funding and project leaders to collectively develop a vision and mission; principles of partnership; a strategic framework, including main program deliverables and objectives; and to plan for engagement with ministries of health, the University of the West Indies (the UWI), local hospital leaders and regional interprofessional specialists. A collective commitment to align with existing Caribbean associations and nongovernmental and intergovernmental organizations was also clearly established.

There have been multiple phases of SCI since the development of the formal partnership between the Centre for Global Child Health at SickKids, the UWI, ministries of health and hospitals at seven sites in the six Caribbean countries (3). Briefly, from 2013 to 2018, SCI focused on the six priorities identified within the needs assessment to develop hematology and oncology capacity, including nursing education; support for local pediatric hematology and oncology clinical care, including education and training for physicians and allied health professionals, and case consultations; local pediatric oncology databases; diagnostic services; care for patients with sickle cell disease; and research and scholarly activities. From 2019 to 2022, the priorities were maintained but regrouped into four categories: education; case consultations; local oncology databases; and research, scholarly activities, policy and advocacy; additionally, there was a pronounced emphasis on sustainability. A total of 8 million Canadian dollars (Can\$) was raised to support SCI's activities from 2013 to 2018 and Can\$ 5 million from 2019 to 2022 via the SickKids Foundation through the generosity of many organizations and individuals in or with ties to the Caribbean, as well as in-kind donations from the partner organizations.

From 2013 to 2022, key activities within SCI have included education and training (for 5 pediatric hematology and oncology fellows and specialized pediatric training for 41 nurses); case consultations and diagnostic services (651 case consultations, support for the completion of 577 specialized diagnostic tests, and support for 831 640 screening tests in Jamaica and

Saint Lucia for sickle cell disease among newborns); development of local oncology databases and tracking systems (886 patients registered); efforts aimed at advocacy and ensuring stakeholder engagement; and coordination of administration, management and funding.

We used data from local oncology databases to calculate the crude incidence rates of childhood cancer, which were 84 cases per million person-years in Trinidad and Tobago, 93 per million person-years in the Bahamas and 110 per million person-years in Barbados (2); however, the databases are hospital-based and do not represent population-based rates. Our rates are lower than those observed in North America (around 150 per million person-years) (4), although we do not know the extent to which our numbers reflect underdiagnosis, underregistration, or out-of-country treatment (2).

Currently, SCI is focusing on long-term sustainability (i.e. continuing the goals of SCI through regional collaborations and local ownership and governance), including ensuring Caribbean-based leadership, with support from SickKids for administration, case consultations, training fellowships and the pediatric oncology databases. An endowment has been established by the SickKids Foundation to support these ongoing activities. Furthermore, SCI's partners work individually and collectively to engage their local ministries of health and regional intergovernmental and nongovernmental organizations, such as the Caribbean Public Health Agency and the Pan American Health Organization, to sustain and build on the gains that have been made.

## KEY ACTIVITIES

Five areas of focus support the primary aims of SCI.

### Education and training

Given the discordance between the number of trained health care professionals and patient load in the partner Caribbean countries, SCI has offered multiple forms of education and training (5). These include formal training for pediatric hematology and oncology fellows, generation and delivery of a specialized nursing curriculum focused on pediatric hematology and oncology, different informal training opportunities (e.g. participation in professional groups, courses and conferences) and quality improvement initiatives.

SCI has provided five fellowships to train pediatric hematologists and oncologists at SickKids (for three doctors from Jamaica, one from Barbados and one from Trinidad and Tobago), and a sixth fellowship is ongoing. Each fellowship lasts for 2 to 3 years and includes instruction in and testing on core topics, laboratory diagnostics, performance of procedures, training in conducting research, and following up with patients through a continuity clinic. The pathophysiology of pediatric hematological and oncological disorders is also covered in detail, with an emphasis on the clinical management of relevant disorders. Fellows receive a certificate of completion, confirming the number of years spent training, and those who complete 3 years are eligible to take the Royal College subspecialty examination in hematology and oncology. Additionally, 41 nurses have received specialized education in pediatric hematology and oncology nursing (i.e. the post-registration diploma in pediatric hematology and oncology nursing) through the UWI,

which includes in-person training in Trinidad and Tobago. This 1-year program is accredited and includes foundational nursing concepts, such as family-centered care, pain management, pediatric health assessment, specialist hematology and oncology nursing practice (e.g. providing supportive care, common pediatric cancers and blood disorders, safe handling of chemotherapeutic agents, and oncology emergencies) and leadership in nursing. Notably, in-country personnel retention rates (i.e. staff who have remained in country after receiving specialized training) have been high, meaning that those with specialized skills have continued to practice in their country. With respect to sickle cell disease, there has been an emphasis on training to screen newborns (e.g. learning about heel-prick techniques and cord blood collection, and the development of a clinical care manual and patient education packages), providing comprehensive care and training about hydroxyurea treatment.

### Case consultations and diagnostic services

Physician-to-physician case consultations have been facilitated within SCI to improve exposure to and review of challenging and rare presentations (6). These consultations have included specialist hematologists and oncologists at SickKids and treating hematologists and oncologists in the Caribbean, as well as other health professionals when appropriate. The case consultations serve as a teaching tool and a forum for discussing diagnostic approaches, treatment options and management plans. Complex cases were selected for presentation at rounds, which further underpinned training and continuing professional development. Telecommunications facilities were installed to support these activities early on, although later there was a shift to internet-based platforms. An output from the case consultations was the development of a repository of evidence-based guidance documents about clinical and supportive care, adapted to the local setting.

Limitations in access and resources (e.g. limited stock, lack of infrastructure) could present challenges to partner countries. For example, some specialized tests necessary for accurately diagnosing patients and informing their treatments are not always available in country (e.g. for performing flow cytometric analysis of blood and bone marrow samples, cytogenetics, immunohistochemistry, targeted gene panels). To address this, a mechanism has been established by which biological specimens are submitted to SickKids and SCI-approved reference laboratories for histopathological or molecular pathology testing, or both. These processes are coordinated by dedicated administrative and laboratory personnel, and the sharing of radiographic images and test results is facilitated by the Secure File Transfer platform (Biscom, Westford, MA, USA), which importantly offers a secure and encrypted means through which information can be shared and accessed. Improving local laboratories remains a priority for the government in each partner country. Since case consultations occur at SickKids, this has been the base for coordinating SCI processes. Local coordination and adherence to protocols have become the responsibility of each site.

### Development of local oncology databases

To improve understanding of the incidence and burden of childhood cancer among SCI's partner countries,

hospital-based oncology databases were developed and have been maintained to generate high-quality data (7). Prior to SCI's activities, there was no formal pediatric oncology database at any of the seven hospital sites. Each site owned their own data, which was entered and stored using the Research Electronic Data Capture (or REDCap, Vanderbilt University, Nashville, TN) electronic data capture tool. Bylaws were established to guide information-sharing between sites through central coordinators. Data entered include both retrospective cases (to 2011) and newly diagnosed cases. To limit the number of routinely collected variables, validity was prioritized over quantity. Collected variables include demographic information (i.e. age, sex, geographical location, socioeconomic status), disease status (i.e. histology, topography, stage), treatment (i.e. modalities, and initiation and completion dates of initial treatment plan) and outcomes (i.e. events, deaths, cause of death, date of last follow up) (2). Key events include death, relapse, disease progression, second malignancies, upfront refusal of initial therapy and treatment abandonment. Developing the databases included making improvements to infrastructure and creating methods to enforce the standardized collection of information; providing specialized training for personnel; performing routine maintenance and quality assurance checks; and creating feedback loops to communicate findings to multiple stakeholders.

### Advocacy and stakeholder engagement

Multiple activities involving diverse internal and external stakeholders were used within SCI to advocate for improvements to the health and quality of life of children with cancer and blood disorders in the Caribbean (8). These activities spanned from engaging with other allied health professionals to developing partnerships with international agencies (e.g. the Pan American Health Organization's Childhood Cancer Working Group for Latin America and the Caribbean) to advocating with decision-makers (e.g. ministries of health, government officials, local politicians) and liaising with civil society organizations (e.g. public interest groups, nongovernmental organizations). A clear advocacy agenda was developed early on within SCI, which helped to foster buy-in and ownership among local partners and create a unified approach.

### Administration and funding

To carry out the diverse activities within SCI, an embedded, interdisciplinary governance structure was developed to provide oversight and enhance accountability (3). This includes ensuring general administrative support for day-to-day operations, working to ensure the ongoing engagement of partners (e.g. through meetings and events, and development of workplans), developing and maintaining communication plans, offering oversight of financial and human resources, and leveraging funding to achieve agreed program deliverables. Administration and management functions have been primarily based at SickKids, with some additional support provided by SCI-funded nurse coordinators at partner institutions. Ensuring that there are dedicated funds to carry out the primary aims of SCI is fundamental to its operations, and they are provided via the SickKids Foundation, an independent charitable foundation committed to raising funds on behalf of SickKids.

## SUMMARY

The SCI partnership was established to build sustainable, local capacity to diagnose, treat and manage pediatric cancers and blood disorders in the English-speaking Caribbean. The key activities within SCI are based on the expressed needs of its Caribbean partners, and include opportunities for reflection, process evaluation and goal-setting. Access to services for children with cancer and blood disorders has been enhanced by providing training and education in hematology and oncology, nursing and laboratory services. Additionally, ensuring that best practices are adopted has been facilitated by developing local, hospital-based oncology databases and adapting treatment protocols for local use. The integration of communication between partners was important for generating a regional community of practice, which has further strengthened the exchange of knowledge and fostered regional and global linkages. In the present, regionally led phase of SCI, management has been decentralized from Canada to the Caribbean partners, with some shared administration and case management. The leads in the Caribbean work individually and collectively to leverage their community of practice to provide regional support and to advocate for

local and regional governmental and nongovernmental support around pediatric cancer and blood disorders. Continued efforts and advocacy will be important in maintaining and building on the improvements in outcomes observed among children aged <18 years with cancer and blood disorders in the area.

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## La iniciativa SickKids para el Caribe para mejorar la atención a pacientes pediátricos con cáncer o trastornos hematológicos

### RESUMEN

Las colaboraciones de instituciones de recursos bajos y altos dentro de los sistemas de atención de salud tienen un potencial reconocido para mejorar las respuestas a los tratamientos hematológicos y oncológicos pediátricos. La iniciativa SickKids para el Caribe es una asociación entre profesionales de la salud del Hospital for Sick Children de Toronto (Canadá) y siete instituciones de seis países del Caribe (Bahamas, Barbados, Jamaica, Santa Lucía, San Vicente y las Granadinas y Trinidad y Tabago). El objetivo principal de la iniciativa SickKids para el Caribe ha sido mejorar la respuesta a los tratamientos y la calidad de vida de los menores de 18 años del Caribe con cáncer o trastornos hematológicos. En este artículo se describen cinco actividades clave emprendidas en el marco de la iniciativa SickKids para el Caribe, consistentes en impartir formación y capacitación, prestar asistencia en materia de consultas de pacientes y servicios de diagnóstico, crear bases de datos locales en el área de la oncología, participar en actividades de promoción y garantizar la participación de las partes interesadas, y coordinar la administración y gestión de proyectos.

### Palabras clave

Región del Caribe; oncología médica; enfermería oncológica; hematología; anemia de células falciformes; pediatría; educación médica; base de datos; defensa de la salud.

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## Iniciativa SickKids no Caribe: melhorar o atendimento a crianças com câncer e doenças hematológicas

### RESUMO

Há um potencial reconhecido para parcerias entre instituições com poucos e muitos recursos dentro dos sistemas de saúde para melhorar os resultados de hematologia e oncologia pediátricas. A iniciativa SickKids no Caribe é uma parceria entre profissionais de saúde do Hospital for Sick Children em Toronto, Canadá, e sete instituições em seis países do Caribe (Bahamas, Barbados, Jamaica, Santa Lúcia, São Vicente e Granadinas e Trinidad e Tobago). O objetivo principal da iniciativa SickKids no Caribe tem sido melhorar os desfechos e a qualidade de vida das crianças caribenhas com menos de 18 anos que têm câncer e doenças hematológicas. Este artigo descreve cinco atividades principais realizadas no âmbito da iniciativa SickKids no Caribe: oferecimento de educação e capacitação; assistência em consultas de casos e serviços diagnósticos; desenvolvimento de bancos de dados locais em oncologia; promoção da causa, assegurando o envolvimento das partes interessadas; e coordenação da administração e da gestão de projetos.

### Palavras-chave

Região do Caribe; oncologia; enfermagem oncológica; hematologia; anemia falciforme; pediatría; educação médica; base de dados; advocacia em saúde.

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