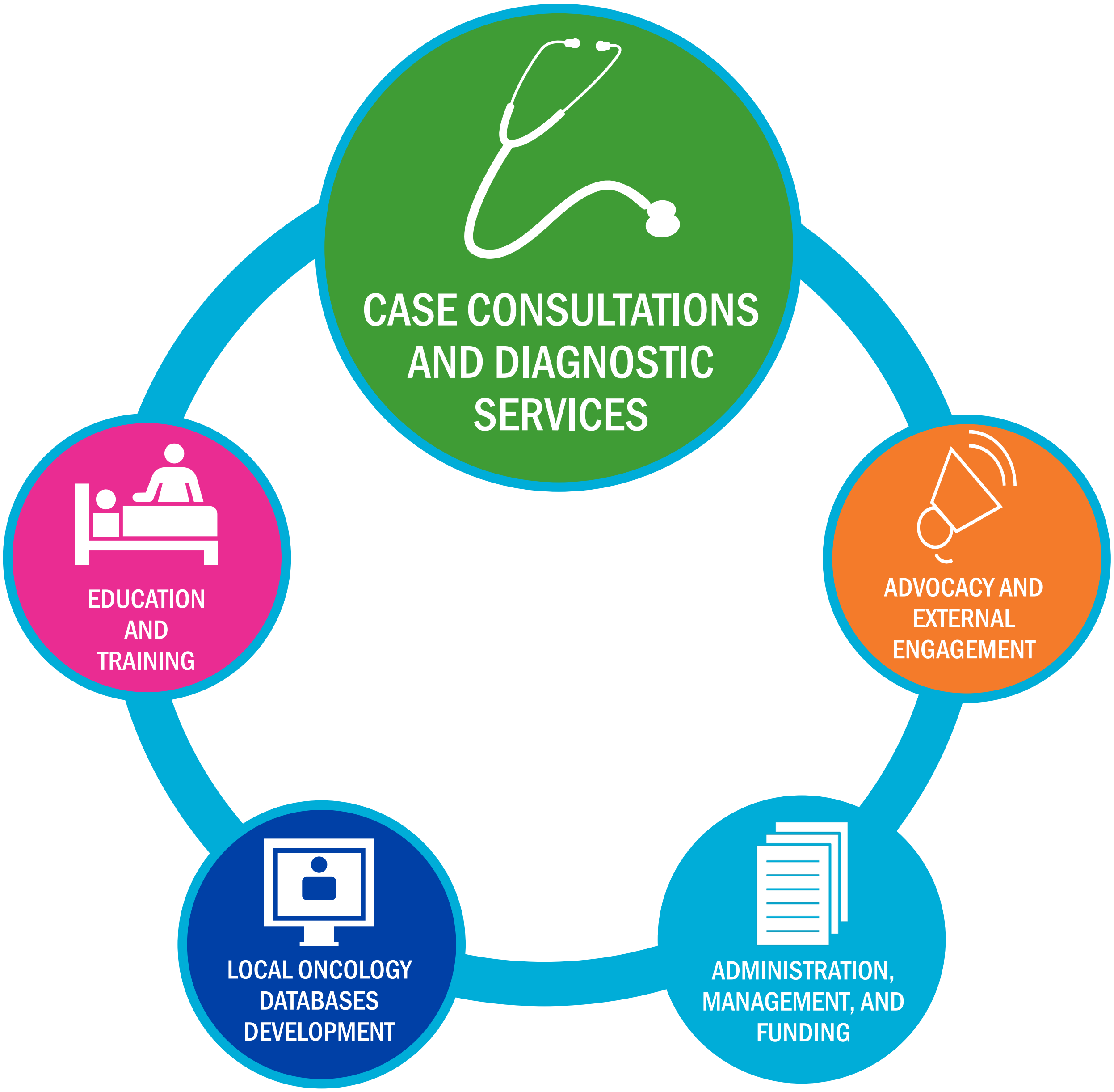
SCI

SickKids-Caribbean Initiative

Enhancing Capacity for Care in
Paediatric Cancer and Blood Disorders

Reflections on the SickKids-Caribbean Initiative:

Case Consultations and Diagnostic Services



CASE CONSULTATIONS AND DIAGNOSTIC SERVICES

ADVOCACY AND EXTERNAL ENGAGEMENT

ADMINISTRATION, MANAGEMENT, AND FUNDING

LOCAL ONCOLOGY DATABASES DEVELOPMENT

EDUCATION AND TRAINING

Reflections on the SickKids-Caribbean Initiative: Case Consultations and Diagnostic Services

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This document is part of the Reflections on the SickKids-Caribbean Initiative technical papers. It is one of five papers published separately, which include:

- Administration, Management, and Funding
- Advocacy and External Engagement
- Case Consultations and Diagnostic Services
- Education and Training
- Local Oncology Databases Development

Recommended citation:
Thame M, Baxter JB, Alexis C, Allen U, Bartels U, Bodkyn C, Bouffet E, Browne-Farmer C, Brzezinski J, Carcao M, Craig J, Denburg A, Dindial K, Mclean-Salmon S, Orrigio K, Read S, Reece-Mills M, Sin Quee C, Smith B, Tsang DS, Waye JS, Wharfe G, Blanchette V. Reflections on the SickKids-Caribbean Initiative: Case Consultations and Diagnostic Services. Toronto: Hospital for Sick Children; 2023.

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Abstract

Within medicine, partnerships between institutions can offer an important mechanism for exposure to and review of challenging and rare case presentations. This technical paper describes the activities and lessons in implementing a case consultation and diagnostic service referral system between physicians and allied health professionals in Canada and multiple countries in the English-speaking Caribbean, known as 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 used case consultations to provide support and enhance the training and decision-making autonomy of pediatric hematologists/oncologists based in the Caribbean. Given resource constraints, mechanisms to access diagnostic services were also developed. Importantly, this collaboration strengthened local and international communities; centered around developing local capacity; supported and strengthened health systems as appropriate; and fostered robust and contextually-appropriate delivery of care.

Introduction

There are recognized inequalities in specialized medical training, development opportunities, and resource availability depending on where one practices in the world (Kellie and Howard 2008). Resources are disproportionately centralized to the Global North compared to the Global South. In some settings, this has led to the development of partnerships between resource-abundant and resource-constrained institutions to improve the quality of care, local knowledge through further education, and infrastructure (Antillon et al 2005; Aristizabal et al 2015).

Within medicine, case consultations (CC) between practitioners and/or allied health professionals can offer an important opportunity to collectively reflect on specific medical presentations, clinical events, or situations. Historically, case consultations have been performed in a face-to-face forum, but as medicine has advanced and technology has developed, consultations are increasingly being conducted virtually (Qaddoumi et al 2007; Adler et al 2015; Amayiri et al 2017). A virtual platform allows for a much wider consultation to occur, as health care workers with various ranges of expertise and in different locations can be involved in the discussion, with the aim of formulating the best possible diagnostic/management plan for a better outcome. In pediatric hematology/oncology, a CC approach is often employed when there is a challenging case presentation to discuss diagnostic approaches, treatment options, and management plans.

CCs can be used as a teaching tool, either to guide teams who may not have expertise in a particular area or exposure to a high volume of cases, or to foster knowledge, skill development, and confidence. This is of noted benefit when rare or challenging cases arise. In the English-speaking Caribbean, specialized training is available locally to medical doctors in areas such as pediatrics, obstetrics and gynecology, and surgery. However, specialization in hematology/oncology is typically targeted to the adult population, and not pediatrics. It is widely acknowledged that pediatric hematological and oncological cases present differently, such that pediatric cases require different diagnostic, treatment, and follow-up plans compared to adults (Kattner et al 2019).

This technical paper focuses on the activities and learnings related to the development of CC and diagnostic services within a collaborative pediatric hematology/oncology partnership between medical professionals in the Caribbean and Canada.

Overview of SCI and Program Components

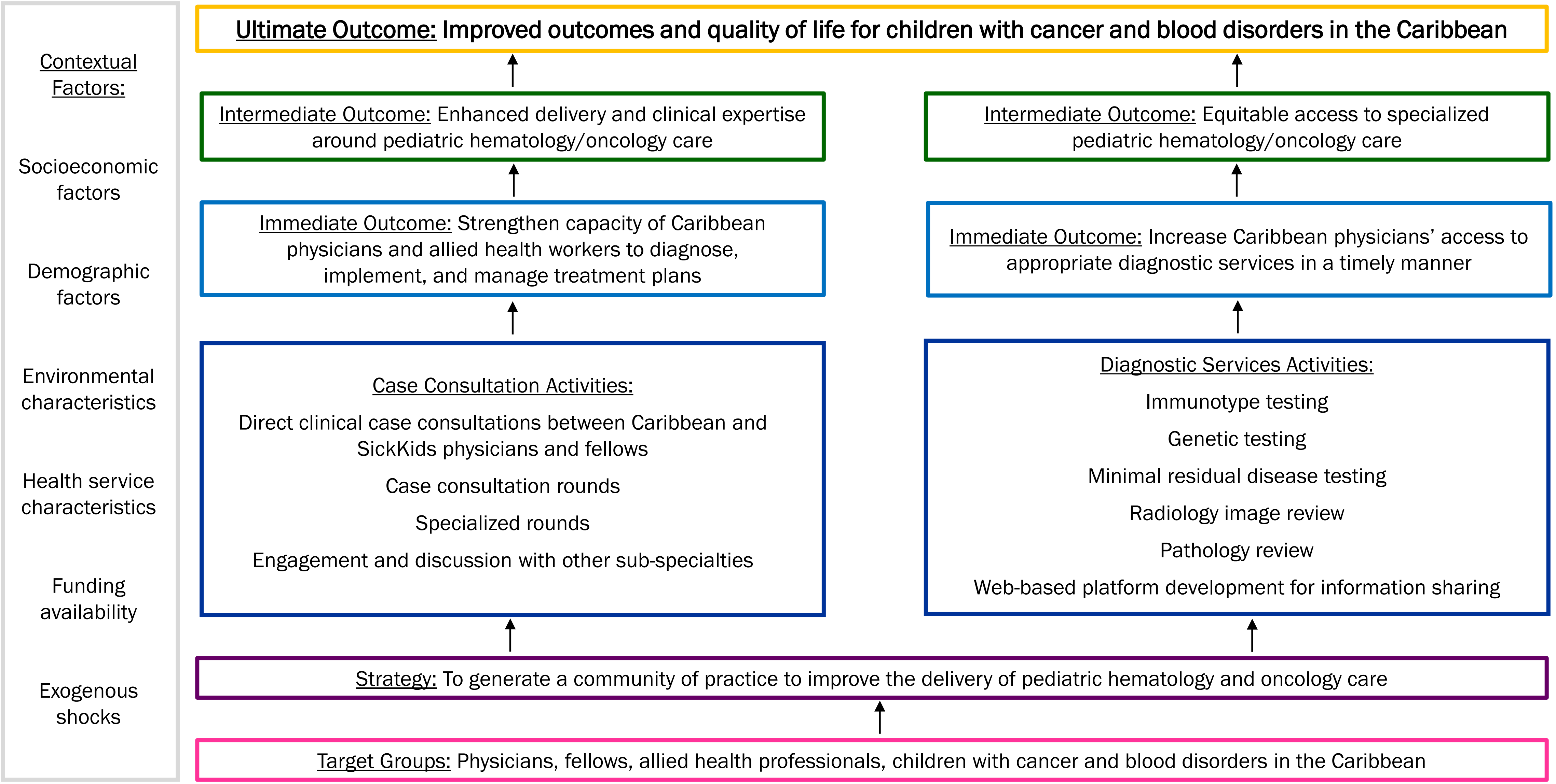
SickKids-Caribbean Initiative Overview

Formally launched in 2013, the SickKids-Caribbean Initiative (SCI) is an innovative 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 skills in the specialty of pediatric hematology/oncology; 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 routine oncology data collection and a corresponding hospital-based pediatric oncology database.

Case Consultations and Diagnostic Services

Case consultations (CC) and diagnostic services underpinned the training and continuing professional development offered within SCI and there were several activities involved **(Figure 1)**. Collectively, these activities contributed to short- and long-term outcomes to improve pediatric hematology/oncology case management, care, and diagnosis. Details specific to the training and fellowship program tied to the CCs have been described elsewhere (Reese-Mills et al 2022).

Within the CC, designated Caribbean physicians were able to electronically submit cases for consultation with the partner SickKids physicians. CCs were submitted after local consultation among those in the Caribbean, such that challenging and rare clinical presentations were reviewed together (e.g., imaging, pathology reports), and discussed



Contextual Factors:

Socioeconomic factors

Demographic factors

Environmental characteristics

Health service characteristics

Funding availability

Exogenous shocks

Ultimate Outcome: Improved outcomes and quality of life for children with cancer and blood disorders in the Caribbean

Intermediate Outcome: Enhanced delivery and clinical expertise around pediatric hematology/oncology care

Intermediate Outcome: Equitable access to specialized pediatric hematology/oncology care

Immediate Outcome: Strengthen capacity of Caribbean physicians and allied health workers to diagnose, implement, and manage treatment plans

Immediate Outcome: Increase Caribbean physicians' access to appropriate diagnostic services in a timely manner

Case Consultation Activities:

Direct clinical case consultations between Caribbean and SickKids physicians and fellows

Case consultation rounds

Specialized rounds

Engagement and discussion with other sub-specialties

Diagnostic Services Activities:

Immunotype testing

Genetic testing

Minimal residual disease testing

Radiology image review

Pathology review

Web-based platform development for information sharing

Strategy: To generate a community of practice to improve the delivery of pediatric hematology and oncology care

Target Groups: Physicians, fellows, allied health professionals, children with cancer and blood disorders in the Caribbean

Figure 1. Framework of activities and outcomes within SCI related to case consultations and diagnostic services

with respect to technical guidance, management, and treatment regimens (e.g., local surgical intervention, radiation therapy, chemotherapy protocols). From a diagnostic standpoint, as comparable infrastructure and technologies were not always available in the local setting, biological samples could also be submitted to SickKids or other selected SCI-approved reference laboratories for testing (e.g., the hemoglobinopathy reference laboratory at McMaster University in Hamilton, Ontario, the reference coagulation laboratories at St. Michael's Hospital in Toronto, Ontario and Queen's University in Kingston, Ontario), thus allowing for the pooling of expert diagnostic resources. Rounds pertaining to complex cases were also a core component and offered a regular contact point and learning opportunity for all involved, and their frequency increased as necessary and required (i.e., monthly or weekly).

Case Consultation Rounds and Related Activities

Given the limited human resources available in the Caribbean setting, the traditional tumor board model often used in resource-abundant settings was found to be impractical. Instead, a model encompassing physician-to-physician consultation was adapted as necessary, and could include allied health professionals on an *ad hoc* basis. The most common cases submitted for review included solid tumors, leukemia/ lymphoma, and hematology **(Table 1)**. Because cases that were more complex in nature were considered for the CC rounds, those in attendance could include a multi-disciplinary team of health professionals with expertise relevant to the case, such as surgical (e.g., orthopedics, urology, ear, nose, and throat, general surgery), rheumatological, immunological, infectious diseases, and nephrology. CCs were intended to be led by the Caribbean-based partners, and as the partnership developed, hematology/oncology fellows from the Caribbean came to take a leadership role throughout the CC process. Under the mentorship of the SCI Medical Director, and working closely with the SCI case coordinator and other assigned experts, the fellows led triaging, reviewing, and creating recommendations. This further enhanced their learning and development towards becoming independent expert consultants. Where appropriate, SickKids experts could also provide radiological image and pathology review, as well as some additional testing, depending on the availability of materials in the Caribbean. Between rounds, continued support occurred as appropriate. Best efforts were made to ensure that any resources discussed were contextually relevant to the Caribbean setting.

Table 1. Breakdown of the SCI case consultations by type (from project beginning to March 31, 2022)

Case Consultation Specialties	Number of Cases Reviewed
Solid Tumour	215
Leukemia/lymphoma	208
Hematology	119
Neuro-oncology	100
Other	9
Total	***651***

Diagnostic Services

Because of access and resource limitations (e.g., limited stock, lack of infrastructure), some specialized tests necessary for accurate diagnosis and informing pediatric hematology/oncology treatments were unavailable locally. In the case of a resource limitation, diagnostic services were made available to Caribbean-based partners through SickKids. This meant that relevant biological samples were shipped from the Caribbean to Toronto to undergo histopathologic and/or molecular pathology assessment. The extent to which this occurred depended on the characteristics of the case and the Caribbean country. This process was augmented by dedicated administrative and laboratory personnel and required coordinated efforts both in Canada and the Caribbean to ensure timely shipment, receipt, and processing of specimens. The most common diagnostic test required was flow cytometric analysis of blood and bone marrow samples, for the diagnosis of leukemia and lymphoma, while other diagnostic services could include cytogenetics, immunohistochemistry, and use of targeted gene panels.

Administrative and Infrastructure Support

In order to facilitate the CC rounds and secure sharing of patient-related information between the Caribbean- and Toronto-based partners, supportive infrastructure, and administrative assistance were required. To facilitate the CCs, telecommunications facilities were installed (Adler et al 2015). This was particularly important to those living on the smaller islands with limited resources, where they might be the only specialist in their field. In more recent years, and with the advancement of technology, there has been a deliberate shift to include internet-based platforms (e.g., Zoom). With respect to radiographic image sharing and diagnostic services, it was also necessary to use an encrypted, secure file transfer platform to share patient-related information for respective CCs. Secure File Transfer (SFT) offered a centralized platform for those who were identified as a part of a case consult team to upload and view any related imaging, tests, and reports. SFT importantly included an integrated comments function for all health care experts to use, and included automated notifications when a new comment was added. Dedicated administrative support and coordination provided by the SCI case coordinator was essential to ensure that CCs happened at regular and timely intervals, and that all information was shared with relevant individuals and reference laboratories to facilitate testing and results requested within the diagnostic services.

Financial Support

Financial support for CCs and diagnostic services was a blend of in-kind support via SickKids and direct-cost recovery via SCI project funds. CCs and diagnostic services could be broken down into three components: 1) specimen shipping; 2) diagnostic analysis; and 3) medical consultation and reporting. All specimen shipping costs were covered using SCI funds. The SickKids Department for Paediatric Laboratory Medicine was instrumental in providing diagnostic support, with diagnostic services covered using a cost recovery model that included the cost of reagents and consumables, as well as laboratory technologist time, given that SCI was a revenue-neutral project. The medical consultation and reporting support for CCs provided by the SickKids Department of Hematology/Oncology used a hybrid cost recovery model. To manage costs, SCI provided the Department with a set amount per case, based on the assumption that cases would require three-hours of physician consultation time. These funds were leveraged within the Department to support continuing medical education activities for all staff. Pediatric cancer and blood disorder consultations required significantly more than three-hours of support, as the cases sent to SickKids through SCI were unique, complex, and often required ongoing consultation for numerous months until an outcome was achieved. This additional time was provided in-kind by SickKids, as it was felt that this activity was a strong source of physician engagement, leveraged existing departmental capacity, and aligned strongly with SickKids vision of “Healthier Children, A Better World.” SCI also directly supported the case coordinator and medical director (part-time), both of whom were instrumental in triaging the cases to the relevant SickKids consultants.

Methods

To inform this technical paper, we reviewed past internal and external SCI reports, including the independently prepared midterm and final evaluations (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

Communities versus Silos

Prior to the development of SCI, communication between the different partner countries existed to varying degrees. In some countries, there was a limited number of medical professionals, which could lead to a sense of isolation. Those who worked alone pre-SCI reported that it could reduce morale and lead to frustration, particularly if there were limited resources. However, the formal and informal communities formed within SCI around patient care were noted to decrease the effect of such stressors and create a sense of belonging.

In particular, the CCs were felt to offer an opportunity to build both Canadian-Caribbean and Caribbean-Caribbean communities. From a Canadian-Caribbean lens, the trust-based relationships that formed over time around the discussion and management of pediatric patients strengthened patient care, as well as offered a platform to share and reflect on thoughts and professional concerns. The development of trust was considered a core component to generating a true partnership. General discussions and knowledge gained through the CCs, supported administratively by reliable logistics and an organized flow of information, were recognized by all to be of benefit. From the perspective of the Caribbean-Caribbean communities formed, SCI facilitated the sharing of information within and between islands that previously occurred on a limited basis. This fostered an awareness of the similar limitations in different settings, and offered joint opportunities for learning. As such, the CCs became a regional forum for the discussion of cases, education, and up-to-date information.

The CCs also provided an important opportunity for interdisciplinary health professionals to support each other in the process of advancing patient care. They presented an opportunity to get the key members of the multidisciplinary team (e.g., hematologists, oncologists, surgeons, radiation oncologists) in the same “room” to discuss and agree on plans for patients. Given that health systems are often over-burdened in resource-constrained settings, it could be challenging to arrange a single meeting where everyone was available. Accessing and commenting via the SFT platform greatly assisted this. This was particularly helpful for developing a consensus plan around diagnosis and management of the case that could be reviewed and updated as required.

Building Local Capacity versus Parachuting in

Because a goal of the CC within SCI was to strengthen the Caribbean physicians' ability to independently manage pediatric hematology/oncology patients, it was essential to provide consultation opportunities to improve local capacity and expertise. Instead of developing a program reflecting priorities identified by those in Canada, the Caribbean partners played an important role in guiding and shaping ongoing discussions. This fostered their decision-making ability and self-confidence, but also offered comfort in knowing that supportive expertise was available.

Within the CCs, difficult and complex cases were identified and presented by those in the Caribbean to those at SickKids. As such, Caribbean physicians took a lead role, as well as following up on recommendations and progress, and those at SickKids offered highly valued expert advice. In supporting the Caribbean physicians around treatment approaches, referring physicians were engaged as an important part of a multidisciplinary team, and not simply expected to follow instructions from external experts without their thoughts and insight around possible limitations being considered. Because there are disparities between the health systems and availability of complex care in Caribbean and Canadian contexts, there was a need to balance and ensure recommendations were feasible. Alternatively, feedback received suggested that having more pre-specified points of engagement along the patient care trajectory and consistent updates as cases evolved could have further bolstered local ownership and responsibility. Of note, there were instances where the Caribbean-based team were able to leverage the connection with SickKids to take initiative and acquire specific resources. This included advocating for access to specialized diagnostic services not available locally and/or recommended medications, as well as clarification of complex treatment plans, which for children with cancer could involve surgical interventions and use of radiation therapy.

There was an emphasis within SCI on the use of local diagnostic services and expertise, where available, and as the initial point of contact. This allowed that these services be developed, as opposed to exporting every test or investigation. Given resource constraints, there have been some concerns around autonomy going forward, as complex cases requiring specialized diagnostic tests and/or medications may present financial challenges or be unavailable in the Caribbean context. This aspect is considered further in the Discussion. With respect to surgery, specifically, it was felt that there was still work to be done in building capacity in the Caribbean, particularly around the availability of reliably equipped surgical theatres. As the limited theatres have to be shared between many surgical specialties, operation time was limited and there could be delays. Alternatively, stemming from discussions within the CCs, context- and disease-specific protocols were also developed by those in the Caribbean, as further explored in the technical paper entitled Education and Training (Reece-Mills et al 2023).

Strengthening versus Supporting Health Systems

Efforts were made both to support and strengthen health systems with respect to CC and diagnostic services within SCI. Early on, it was necessary to provide infrastructure, such as telemedicine equipment to enable the conduction of CC, as some sites did not have the facilities necessary to support participation. Once established, the emphasis shifted to improving organizational flow and delivery of services (i.e., strengthening). Importantly, there were efforts made to help local practitioners advocate for better support and local resources as required.

With respect to diagnostic services, resource constraints continue to present an important barrier, thus the focus has been more on providing support and resources. This is particularly with respect to highly specialized laboratory services, where there remains a need to develop procedures and tests such that they meet accreditation standards of international review bodies. For example, an initial goal had been to establish flow cytometry testing at two SCI-affiliated sites (National Public Health Laboratory, Jamaica, and Mount Hope Hospital, Trinidad and Tobago), although rollout was met with barriers. In Jamaica, flow cytometry testing was successfully established at the National Public Health Laboratory, but reagent availability presented a challenge to reliably providing the service. Also, there were problems with establishing international accreditation, such as with the College of American Pathologists (CAP), something needed for providing a service for other countries. Flow cytometry allows for the characterization of subtypes of childhood leukemia (e.g., B- versus T-cell acute lymphocytic leukemia). However, because of operational limitations, particularly lack of essential reagents, facilities that had flow cytometry testing were often non-operational. In part, this can be attributed to lack of government funding availability for public laboratory services and specialized training for laboratory hematopathologists. Because childhood leukemia is the most common and curable of childhood cancers, such diagnostic tests should be considered standard of care (Friedmann and Weinstein 2000). Given that offering and maintaining such specialized diagnostic service has cost implications, the development of a regional approach may offer further benefit. Engaging governments and health systems will be critical to improving access to diagnostic service infrastructure.

Optimized versus Routine Practices

While early on in SCI CC and diagnostic services were largely run by SickKids, much effort has been made around understanding local and regional needs and resources, including between island differences, to optimize patient treatment and outcomes. Protocol and policy developments and adaptations based on the local and regional resources and requirements were key components to optimizing practices, and the effort in doing so was highly collaborative. The CC and diagnostic services evolved significantly over the course of the project, facilitating a much more efficient, accessible, and transparent process. This required reflection on existing policies and protocols in place in the Caribbean context to identify where improvements might occur, understanding that the standard of care in Canada was not realistic in the local setting. Identifying local leaders and the formation of working groups that met regularly to review progress and identify changes was important.

Discussion

Overall, having dedicated resources was core to the success of the CC and diagnostic services. This included having contact with medical professionals with relevant expertise; reliable administrative support to aid follow-through and maintenance of communication; and ensuring access to necessary infrastructure and materials. While early on in the partnership the CCs were largely facilitated by those at SickKids, there was a transition to leadership among those in the Caribbean in selecting and presenting complex cases. As such, those at SickKids came to provide support, enhancing the decision-making autonomy among the Caribbean physicians. With respect to diagnostic services, available resources could limit which tests could be conducted locally, although there was an improvement in laboratory-based diagnostic ability over the course of the partnership (e.g., flow cytometry testing in Jamaica). There were still limitations with respect to sharing the resource with other countries in the region.

Areas that could use further refinement included ensuring all medical professionals involved with a patient’s care were available to participate in the virtual CCs. Busy schedules made this challenging; however, when the pediatric oncologist/hematologist, radiation oncologist, and any surgeons involved could meet together, this was felt to greatly benefit the conduct of a treatment plan. One solution could be developing ongoing communities of practice centered on key groups of patients, including leukemia/lymphoma, solid tumors, brain tumors, hemoglobinopathies (e.g., sickle cell disease, thalassemias), and inherited bleeding and clotting disorders (e.g., hemophilias). Notably, SCI’s work offered collateral, indirect benefits to physicians, nurses, and other allied health professionals outside of pediatric hematology/oncology, as a result of adapted practices by those engaged in SCI.

Despite the tremendous amount of work and the many strides made, there are recognized concerns around sustainability. Key supports to local infrastructure were provided through access to radiological and pathological services at SickKids. However, efforts to translate these temporary supports into enduring clinical programs in the Caribbean context would cement the impact of this support into sustainable health system capabilities over the long-term. Each country, although similar in geographical location, varies with respect to resource capabilities based on financial support, population size, access to expertise, laboratory services, pharmaceutical/drug access, and, most importantly, governmental regulations. Buy-in from local governments will be important to making this possible, yet the efforts to strengthen local infrastructure by governments has been slow despite the impact demonstrated within SCI. Given certain unique circumstances within each country, developing a single model that works for all six countries is unlikely. However, different sites that would not normally share information did so, which created more awareness of similar limitations and provided joint opportunities for learning. This presented an opportunity for sites to support each other in the process of advancing patient care.

The CCs had a significant positive impact for the Caribbean countries. Many children benefitted from the expertise of their local, Caribbean healthcare providers, and from the consults those experts had with their counterparts in Canada. Diagnostic services not accessible locally were made available in Canada to further aid in the diagnosis of many children.

Sustainability is challenging when there is a reliance on experts and diagnostics outside a given country. Going forward, Caribbean physicians engaged in the care of children with cancer and blood disorders will continue to be able to access CCs in Canada, supported by an endowment being established at SickKids. In addition, Caribbean physicians will continue to collaborate with each other to ensure a robust succession plan is in place in each of their own countries. SickKids will continue to support that planning through ongoing funding for pediatric hematology/oncology fellowship study at SickKids. All involved in SCI agree that these supports are critical to maintaining and building on the significant gains made by the SCI collective in diagnosing and treating children with cancer and blood disorders in the Caribbean.

Contributions

MT prepared the first draft of the manuscript, with assistance from JBB. JBB designed the survey, and all remaining authors provided input on the key activities and themes related to the case consultations and diagnostic services within SCI via the survey. All authors read, provided additional feedback, and approved the final draft.

Acknowledgements

Special thanks are due to Dr. Jim Whitlock (Head of Hematology/Oncology), Dr. Gino Somers (Head of the Pathology Department), Dr. Mary Shago (Head of the Cytogenetics Department), and Dr. Manohar Shroff (Head of the Diagnostic Imaging Department) at SickKids for their strong support of SCI—without this level of support from the medical and technical staff in these departments at SickKids, it would not have been possible to provide the high quality diagnostic support and case consultation services that were so greatly valued by local health care professionals involved with the assessment and care of children with cancer and serious blood disorders in the six Caribbean countries. The authors also kindly acknowledge Dr. Sheila Weitzman for her ongoing role in conducting case consultations; Margaret Manley-Kucey for support throughout the manuscript development process; and Melissa Sundardas for support with report formatting. The authors further wish to thank SickKids Foundation and all the generous donors who have contributed to SCI. They especially want to acknowledge the McCaig Magee Family for supporting the initial needs assessment that made SCI possible. Lead donors (in alphabetical order) are David and Christine Anderson; The Bahamas Telecommunications Company Ltd. (BTC); Bruce and Suzanne Bowen; CIBC FirstCaribbean; Andre DeGrasse Family Foundation; Myron and Berna Garron; Kamala Jean Gopie; Wes and Christine Hall; Holowesko Partners Ltd.; LesLois Shaw Foundation; McCaig Magee Family; McPike Zima Foundation; Mining4Life Charity Challenge; N.C.B. Foundation; Wayne and Nigela Purboo and QuickPlay Media; Republic Bank Ltd. (Barbados); Republic Bank Ltd.; Sandals Foundation; Scotiabank; and Derrick and Gay Smith. Every donation, large or small, has helped make the work of SCI possible.

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