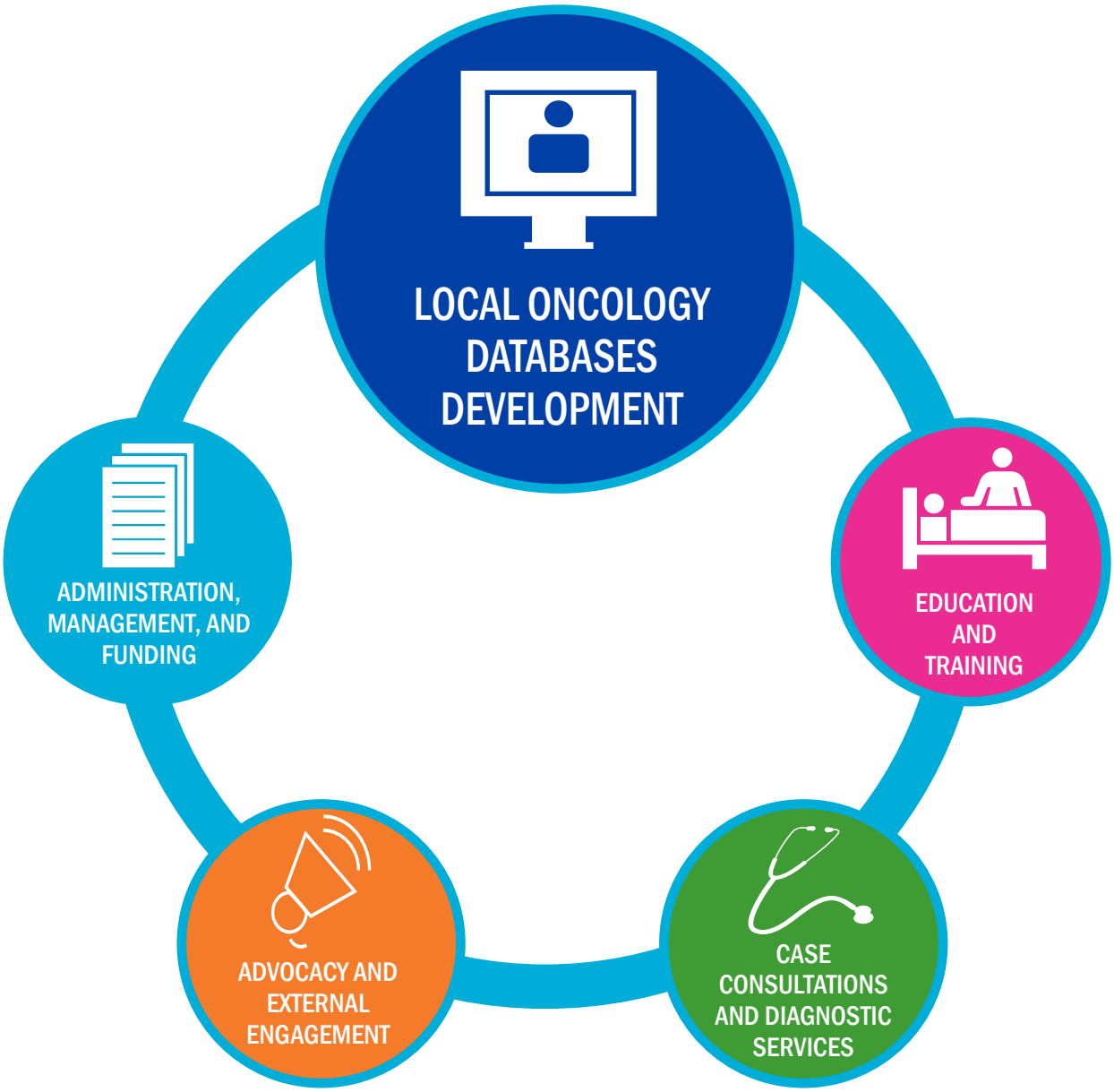
SCI

SickKids-Caribbean Initiative

Enhancing Capacity for Care in Paediatric Cancer and Blood Disorders

Reflections on the SickKids-Caribbean Initiative:

Local Oncology Databases Development



Reflections on the SickKids-Caribbean Initiative: Local Oncology Databases Development

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- Administration, Management, and Funding
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- Case Consultations and Diagnostic Services
- Education and Training
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Abstract

Understanding the incidence and burden of childhood cancer underlies the integration of policy-level changes and healthcare planning. This technical paper describes the activities and lessons in developing a cancer registry through a collaboration between physicians, healthcare professionals, and data managers 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 developed and maintained local oncology databases to capture the incidence of pediatric cancer, enhance the understanding of patient outcomes, and inform treatment-related decision-making. Key elements to support the generation of quality data and overall success of the databases have included standardized collection of information; specialized training of dedicated personnel; prioritizing data validity through routine maintenance and quality assurance; reliable funding; and local ownership, fostered by strong by-laws to guide the sharing of information.

Introduction

To achieve the goal of improving global childhood cancer survival to at least 60% by 2030, there is an acknowledged need to support resource-constrained governments in developing sustainable, high-quality national childhood cancer programs (WHO 2020). Estimates from population-based cancer registries place the global incidence of childhood cancer at approximately 400,000 new cases annually in children 0-19 years (Steilarova-Foucher et al 2017). Experts, however, have long considered that the burden is likely even greater, given that much of the data come from high-income countries (HICs), yet the majority of childhood cancers occur disproportionately in low- to middle-income countries (LMICs) where comprehensive pediatric cancer registries are lacking (Gupta et al 2015). Indeed, recent modeling has estimated that the true burden among children 0-14 years alone may be over 400,000 (Ward et al 2019). Establishing population-based pediatric oncology registries in resource-constrained settings is therefore critical to understanding the true global burden of childhood cancer, and add valuable knowledge of incidence and survival (Valsecchi et al 2008). Common barriers, however, include financial constraints and political indifference.

The English-speaking Caribbean region is home to several jurisdictions classified as “small island states.” The individual island populations are small and ethnically diverse, with noted income inequalities and resource and infrastructure limitations (Spence et al 2019). While there are similar modes of health governance and resources, several factors can present challenges to healthcare delivery among these small island states. Although crude numbers of childhood cancers are small in comparison to larger

countries, the burden of care for these children in the region is no less significant.

Many jurisdictions in this region lack population-based pediatric oncology registries. Hospital-based pediatric cancer registries may be considered as a potential step towards the eventual establishment of a population-based registry. Furthermore, in small populations, like those seen on the islands in the Caribbean, data from hospital-based registries may approach population-based data, especially where the management of pediatric cancer is localized within a single institution (Piñeros et al 2020).

In this brief, we describe the regional and international collaborative process undertaken to generate and manage hospital-based pediatric oncology registries (referred to hereafter as 'local oncology databases') at seven hospital sites in six island nations within the SickKids Caribbean Initiative (SCI). We examine the successes and failures of this venture in the context of enhanced capacity for care of children with cancer and sustainability.

Overview of SCI and Program Components

SickKids-Caribbean Initiative Overview

Launched in 2013, SCI is an innovative nine-year program in six Caribbean countries, focused on improving the capacity of local health care professionals and systems 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), local 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 routine oncology data collection and corresponding databases.

Local Oncology Database Development

Prior to SCI, no formalized pediatric oncology database existed across countries in the English-speaking Caribbean. Launched formally in November 2014, the development and maintenance of the local oncology databases included four core activities: (1) generation of the databases; (2) personnel training and support; (3) ongoing database management; and (4) feedback loops **(Figure 1)**. Importantly, data ownership remained with each respective primary site. Sites agreed to share their data with central coordinators, but this agreement could be revoked at any time.

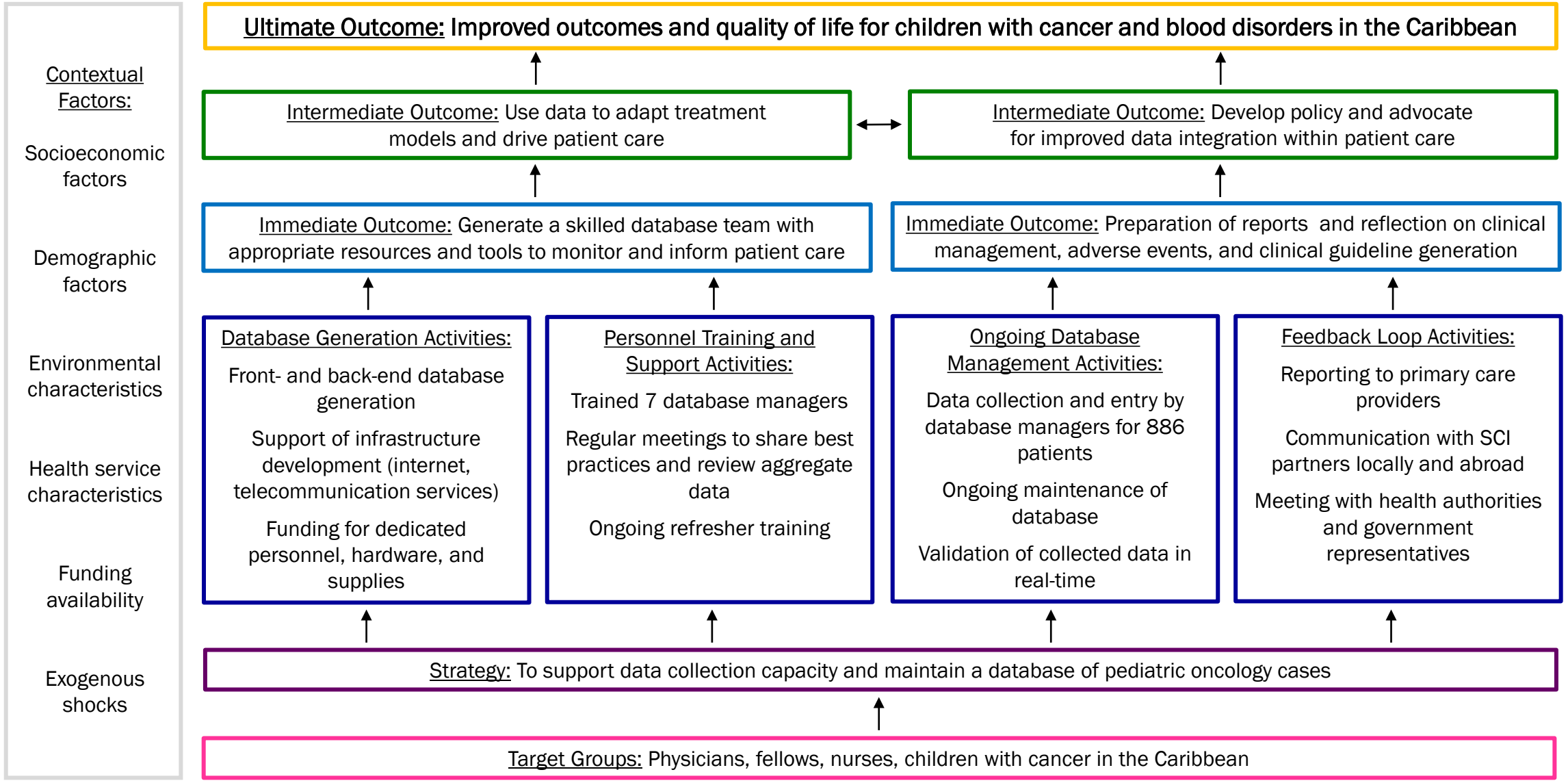

Figure 1. Framework of activities and outcomes within SCI related to local oncology databases generation and maintenance

Database Generation

The databases were generated using the Research Electronic Data Capture (REDCap) electronic data capture tool, which offered a single but shared and secure cloud-based interface to enter and store patient information (Harris et al 2009). This facilitated the accessibility of a common database (data-commons) between country sites. To identify key data variables for routine collection, multiple stakeholders were engaged, including clinicians, academics, hospital administrators, government officials, and when possible, cancer registrars. A core principle was to limit the overall number of data variables collected, prioritizing validity over quantity. Collected data variables included those related to demographics (age, sex, geographic location, socioeconomic status), disease (histology, topography, stage), treatment (modalities, initiation and completion dates of initial treatment plan), and outcome (events, deaths, causes of death, dates of last follow-up) (Gibson et al 2018). Key events included death, relapse, progressive disease, second malignancies, upfront refusal of initial therapy, and abandonment. Given sensitivities around patient data, strict data governance rules, largely dictated by local leads, were established to facilitate trust with stakeholders. Site leads could only access their own site-specific data and were required to approve privileges for anyone requesting access. Similarly, assigned data managers were unique to individual sites and granted site privileges only. Even in countries where more than one site existed, no sharing of data between sites was permitted without the express approval of site leads. Access to aggregated data analyses was facilitated through previously identified overall database co-leads; any proposed analyses required that data be presented in aggregate.

Personnel Training and Support

Dedicated personnel were hired at each site to support the collection and uploading of data. Initial training was held in Toronto in the summer of 2014, with data managers and site leads attending either in person or via teleconference. Data managers were selected by individual sites and represented a mix of clinical and administrative personnel. Beyond practical skills, the training included an introduction to the principles of childhood cancer, data management, and confidentiality. Subsequently, regular meetings provided refresher training and an opportunity to discuss any issues that arose. A common data dictionary allowed each site to produce consistent and comparable information.

Ongoing Database Management and Feedback Loop Activities

Data entry included both retrospective (to 2011) and newly-diagnosed cases. Feedback loops were integrated within reporting, such that real-time validation of data could occur. Data were validated by local clinicians and then validated again by the database co-leads. Queries were returned to data managers in real time. Regular meetings with physicians fostered reflection on and use of the data in practice. There were additionally meetings with multiple stakeholders, both internal and external, such that the data was utilized on an ongoing basis. As such, the data supported reporting on the regional burden of pediatric cancer, as well as informing policy development and advocacy efforts within SCI.

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.

Themes

Communities versus Silos

The generation and management of a medical database can be a siloed experience. However, within SCI, we sought to engage in a collaborative process of establishing local oncology databases across all seven hospital sites in the six island nations in the English-speaking Caribbean. As previously noted, each site was responsible for their own datasets, but these were all accessible via the data-commons.

With this approach, several informal communities emerged over the duration of the project. Data managers were recruited by the site leads, and the training of both data managers and site leads took place as a collective, in-person two-day workshop. As a direct result of this process, we saw the establishment of a strong regional community of database managers supported by site leads. Scheduled quarterly meetings, conducted as part of routine maintenance and quality assurance reviews of the data via teleconference, have encouraged continued collaboration and sharing of ideas amongst managers across all sites, thus strengthening their network and ties to the project. In several sites, data management duties were performed by nurses who formed part of the patient care teams, and who had a natural connection to the databases project.

These nurses could see first-hand how the teams' clinical management translated to palpable data regarding the care of children with cancer in their own countries, and later how analysis of complete datasets could identify quality of care concerns and be a catalyst for change. This importantly contributed to the continued success of the local oncology databases thus far.

While each island maintained individual ownership of their data, the data-commons allowed for review of aggregated, non-site-specific data. Partners felt strongly that this brought the individual sites together as a regional community of pediatric oncology practice, where they could discuss patient outcomes in a non-comparative way. The ongoing collaborative process of validation of data and periodic review of the aggregate dataset at the SCI Annual Meetings has been instrumental in maintaining this support network of pediatric oncology professionals. Additionally, recognizing the need for quality research on childhood cancer management and outcomes in LMICs and small island states, the local oncology databases have allowed SCI partners to come together not just as a community of practice, but as a community of research professionals. There are forthcoming papers detailing the outcomes of children with cancer in the region.

Building Local Capacity versus Parachuting in

Creating local oncology databases was considered by all stakeholders to be a primary objective of SCI, but of all the pillars to be established during the life of SCI, potentially the most difficult to achieve. At the outset, regional partners were concerned about myriad potential barriers to the establishment of successful and sustainable databases. Lack of financial resources to hire, train, and maintain staff for the efficient running of a registry was a major concern. Given the intention to collaboratively establish and maintain the databases with other countries in the region, there was the initial concern that countries' Ministries of Health might have issues regarding data ownership and sharing, and that comparisons between countries could have the potential to create political backlash.

Stakeholders now agree that these barriers have been largely overcome. Caribbean SCI site leads took responsibility for ensuring that all local approvals were obtained to establish the terms of data collection and storage. The carefully conceived data-commons has been effective at keeping data together enough for meaningful analysis but separate enough so as not to jeopardize political relationships. Further, the MOUs could be seen as an acknowledgement of the burden of childhood cancer in the region, whereby childhood cancer registries could better characterize the current state of care. The engagement of these national authorities has been an important step towards the sustainability of the local oncology databases.

While it was necessary to inject funds from SCI into the initial training workshop, the established pool of trained database managers immediately enhanced local and regional capacity for self-sufficient data management in the short-term. Further, the data managers felt empowered to train others, and have already done so in many instances, laying the groundwork for a sustainable pool of this human resource in the longer-term. However, a major roadblock to sustainability remains continued funding for the data manager role. While data entry may be incorporated into future job descriptions of team personnel, attempts are being made to secure philanthropic funding for the continued payment of data managers, beyond SCI, until a more permanent solution is determined.

From inception, regional physician partners were required to play active roles, and these contributions have been voluntary. Each site lead was held responsible for the primary verification and validation of the data entered by their local data managers. This ensured that the data were being kept current and up to international standards, although such checks could be infrequent given competing priorities and significant clinical burden. While secondary validation and analysis were led by an oversight team, inclusive of an international SickKids partner, prioritizing full local ownership of the process was the goal and will be key to ensuring the longevity of the databases beyond the formal SCI partnership. This transition has already begun as Phase 2 of SCI has ended. Primary validation continues to be the responsibility of the regional site leads, but now, a team consisting of only regional partners has been identified for secondary validation and analysis of data. This team consists of one regional physician, who received fellowship training through SCI and has since returned to the region to work, for the secondary validation of data; and a clinical researcher affiliated with the George Alleyne Chronic Disease Research Centre (GA-CDRC) at The UWI, Cave Hill Campus, Barbados for data analysis. Support from the International Agency for Research on Cancer (IARC) has also been sought for assistance with ensuring the sustainability of these databases.

Strengthening versus Supporting Health Systems

As the databases have become better established, previously existing population-based cancer registries in some of the islands see the potential for bolstering the quality of their data by incorporating the local pediatric oncology datasets, and are now entering into collaborations regarding the merging of these databases with their registries. Indeed, the recent onboarding of a researcher from the GA-CDRC to coordinate the data analysis of the entire database in the post-SCI Phase 2 era may facilitate this process. However, it is important to recognize that the purpose of hospital-based registries overlaps but is distinct from that of population-based registries, usually necessitating the collection of more detailed data (e.g., cancer events, some non-stage prognosticators). Any merging of databases will need to take these overlapping objectives into account.

Optimized versus Routine Practices

The goal of any disease-specific medical registry is to collect data that can be utilized to improve outcomes. Several examples of this have occurred during the last several years. For example, early in the project it became clear from data analyses that early treatment-related mortality (TRM) in patients being treated for acute myeloid leukemia (AML) was far higher than expected. This observation allowed for discussion of how early TRM in AML could be curbed. Supportive care guidelines were reviewed (e.g., platelet thresholds that took into account local availability limitations). In addition, a change to a less intensive protocol which had already demonstrated reasonable survival outcomes in countries with similar resources was recommended. Finally, an AML Working Group was established to facilitate early discussion of newly diagnosed AML patients between the managing local team and local and international experts. Though formal analyses are ongoing, initial evidence indicates a trend towards a decrease in TRM rates since these efforts were initiated.

Discussion

The establishment of the local oncology databases was critical to the mission of enhancing capacity for management of childhood cancers and blood disorders in the region, as put forward by SCI. Other major SCI initiatives including advocacy for the development of national and regional childhood cancer plans, improved regional drug access and procurement, continued support for training of specialized health care professionals, and heightened public health awareness are impossible without data to support why these things are necessary.

Key elements essential to the success of the databases included reliable funding for data management; flexibility to house data aggregately in a single, cloud-based platform while maintaining the integrity of each site's data; and strong, ethically generated by-laws guarding the sharing of information. Relationships formed both regionally and internationally throughout the development of these databases were also pivotal to their ongoing success, particularly the support received from government ministries in pursuing the registries and from international communities regarding the development of the data dictionary and standardization of information.

The collaboration between sites on the databases over the nine-year and counting life of SCI has had many important sequelae. Most obviously, we have been able to produce quality data on childhood cancer incidence and outcomes. This is an important achievement given that the under-representation of data on childhood cancer in LMICs and small island states is still a major issue, and estimated to be responsible for 82.2% of global childhood cancer disability-adjusted life years (GBD 2017). The data generated

by SCI has already had major impacts in informing changes to clinical practice in the region. Sustainability of the databases has the potential to lead to further future improvements.

An additional success related to the databases are the communities of practice, which have evolved amongst regional health professionals at all levels. This has been a process of networking and team-reflection. Providers were able to see similarities with their neighboring colleagues and note that they were not alone in the difficulties they faced with management of children with cancer in a resource-constrained setting. The established community of regional data managers, specifically, has been a definite success of SCI's mission.

How, and if, these developments have translated to improved outcomes for children with cancer over the timeline of SCI is difficult to assess given short timeframes and small number of incident cases, but will be the topic of a clinical study. What is unmistakable, however, is the tangible foundation that has been laid for growth through self-evaluation of national and regional health systems. As we move into the sustainability phase of SCI, it will be imperative to sustain the developed databases, although we acknowledge that how this will be achieved has not been definitively resolved. Still outstanding is the need for a clear source of funding for the database managers and other administrative requirements. It is hoped that the alliances formed at the outset of the generation of the local oncology databases, such as with the individual Ministries of Health and the dominant regional institution for tertiary learning, The UWI, as well as newer relationships such as with PAHO and the IARC, will prove to be instrumental in preserving these databases for the foreseeable future.

Contributions

CBF wrote the first draft of the manuscript, with feedback from JBB and SG. JBB designed the survey, and all remaining authors provided input on the key activities and themes related to the local oncology databases via the survey. All authors read, provided additional feedback, and approved the final draft.

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