SICKKIDS-CARIBBEAN INITIATIVE

Final Evaluation Report

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Centre for Global Child Health
at the
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VITUS
RESEARCH &
EVALUATION

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Executive Summary

Evaluation Purpose & Scope

SickKids-Caribbean Initiative (SCI) aims to improve the outcomes and quality of life for children with cancer and blood disorders in the Caribbean. SCI commissioned Vitus Research & Evaluation Consulting to conduct an independent evaluation to answer the following questions:

1. What have been the most important outcomes of SCI to date?

2. Within its current structure, scope, and resources, are SCI activities meeting the needs they have been designed to meet in the region?

3. Has SCI been effectively preparing for the post-SCI phase?

Within this evaluation, 34 individuals participated through interviews (n=17) and surveys (n=17) with a variety of roles represented, including Caribbean physicians and nurses, SickKids nurses and physicians, and members of the project management team. The evaluator also reviewed SCI documents and the relevant research and evaluation literature and conducted meetings with the SCI project management team.

The evaluation criteria used were relevance, effectiveness, coherence, efficiency, and sustainability.

Key Findings

Q1. What are the Most Important Outcomes of SCI to date?

The three most important outcomes associated with SCI according to the participants were:

A. Increased Number of Physicians and Nurses in the Region who Specialize in Paediatric Haematology/Oncology, Helping to Fill a Large Human Resource Gap.

At baseline (2013), there were only three physicians with specialized paediatric haematology/oncology training in the SCI partner countries and no nurses with specialized paediatric haematology/ oncology training. As of July 2020, a total of four additional physicians and 27 nurses in these countries have received the specialized training. By the end of 2020, one more fellow will start her training and 14 more nurses will graduate.

B. Improved Capacity to Diagnose, Treat, and Manage Paediatric Haematology/Oncology Patients.

To date, more than 510 cases have been submitted to SickKids physicians for case consultation. Caribbean physicians said these consultations made a significant difference to patient outcomes. SCI provides free flow cytometry for the six

partner countries. SCI also made it possible for all SCI partner countries to send samples to SickKids Hospital for minimal residual disease testing. As of March 2020, 330 diagnostic tests for patients with leukemia have been conducted.

C. Improved Regional Capacity to Diagnose, Treat, & Manage Paediatric Haematology/Oncology Patients

SCI has transformed what used to be a few Caribbean specialists working in silos into a community of practice that is high-trust, linked to key international groups & organizations, and has led to a series of positive outcomes, including increased collaboration (regional, international, and interprofessional).

Q2. Within its current structure, scope, and resources, are SCI activities meeting the needs they have been designed to meet in the region?

Focus Area: Education & Quality Improvement

Overall feedback on the haematology/ oncology fellowship, nursing education program, telemedicine sessions, and the facility-based training and quality improvement (QI) sessions was positive.

Participation in specialist meetings and conferences has been seen to meet needs. Several barriers outside the control of SCI, related to the recruitment and deployment of nurse graduates, were identified and SCI was encouraged to continue advocacy. Facility-based training and quality improvement were perceived as important but challenging to organize.

Focus Area: Case Consultation

Activities in this focus area were positively rated and were perceived as extremely valuable. It was advised that it is necessary to hold regularly scheduled case consultation rounds on brain tumours because they are rare, and education, repetition, and updates are essential to effective treatment. The clinical and supportive care guidance documents were being used and were deemed valuable.

Focus Area: Local Oncology Databases

Feedback related to the oncology databases was positive. The collection of oncology data has been meeting the needs of the region. To date, 687 patients' data have been registered in the local oncology databases. The collective review of aggregate data and action planning based on it has been useful because of the perception that when the data is aggregated, it becomes more impactful and makes it possible to take a region-wide view.

Focus Area: Research, Policy and Advocacy

To date, there have been 32 SCI-related presentations in international conferences, five SCI publications, and one mid-term evaluation. Some participants thought there was potential for greater output in this focus area. Participants said now that both data (oncology databases, drug availability and access study) and the right linkages (e.g. with PAHO working group) have been created, research and evaluation can be used as strong advocacy tools to influence policy. The meeting organized by the World Health Organization (WHO) and Pan American Health Organization (PAHO) in February 2020 to discuss strategies to improve childhood cancer care in the Caribbean was described as an effective venue to influence health policy.

Q3. Has SCI been effectively preparing for the post-SCI phase?

Participants varied in their sentiments about the level of readiness for transitioning to post-SCI but mentioned the same risk factors and enabling factors for this transition.

Risk factors and challenges included:

- Need for continued government engagement;
- Difficulty articulating the post-SCI strategy;

Executive Summary

- The emotional burden of SCI 'ending' and the risk of losing access to case consultations.

Enabling Factors included:

- A strong foundation built in SCI Phase 1 and Phase 2, including a high-trust community of practice with a pan-Caribbean commitment, and necessary technological infrastructure for collaboration;

- Interest from the business community to fund post-SCI activities.

The key priority transition activities identified included:

- Building the governance structure as a pre-requisite to donor engagement;

- Government engagement;

- Developing the financial model and donor engagement strategy;

- Ongoing monitoring and evaluation, especially in the early stages of the post-SCI phase to inform transition efforts.

Conclusions

Relevance: SCI has been relevant to the needs of its Caribbean partners through creating contextually-relevant tools and considering local resources when determining treatment options and designing educational interventions.

Effectiveness: SCI has been effective; it has achieved its desired outcomes.

Efficiency: SCI has been efficient; as a whole it is meeting its deadlines, and delays that were uncovered were largely outside the control of SCI. However, more dialogue around how to remove barriers for nurses will be beneficial.

Coherence: This evaluation found SCI to be internally coherent, meaning the various objectives and activities fit well together. SCI is also externally coherent, based on the external partnerships uncovered in this evaluation.

Sustainability: Global research has uncovered numerous key factors necessary for the successful transition of global health programs. SCI is doing well on the following factors: partnerships between SCI partners and strategic external partners; regional collaboration; local ownership; communication; and adaptability. It remains to be seen how SCI will build the governance model for post-SCI, the financial model, and the donor engagement strategy.

SCI Final Evaluation: At a Glance

Education & Quality Improvement

- ✓ **4** additional paediatric haematologists/oncologists and **27** nurses with specialized training in paediatric haematology/oncology are providing essential care for children. 14 more nurses will graduate with specialized training in haematology/oncology by the end of 2020.

- ✓ Increased awareness building about hydroxyurea through education sessions and quality improvement initiatives has led to increased use of the drug which has contributed to improved care & outcomes for patients with sickle cell disease.

- ✓ What used to be a few siloed specialists in the region has transformed into a community of practice that:
  - Is trust based;
  - Is linked to key international groups & organizations, including SickKids;
  - Has led to increased collaboration (regional, international, and interprofessional), reduced isolation, multi-directional learning, and other benefits.

Research, Policy, & Advocacy

- ✓ 32 presentations and 5 publications.
- ✓ Now that both the data (oncology database, drug availability and access study) and the right linkages (e.g. PAHO working group) have been created, research and evaluation can be used as strong advocacy tools to influence policy.
- ✓ SCI should continue to advocate for equitable access to diagnostic services for all children in the region.

Local Oncology Databases

- ✓ 687 patients registered in 7 local databases.
- ✓ Data led to identification of high-risk AML patients and prompted intervention.
- ✓ Data was reported to have improved clinical decision making.

Case Consultations

- ✓ Access to diagnostic expertise and technology has had a direct positive impact on treatment and management of paediatric patients.
- ✓ 510 case consultations conducted.
- ✓ Flow cytometry testing is available free of charge, through SCI, for all children in SCI partner sites.
- ✓ 330 specialized diagnostic tests conducted.
- ✓ 93,868 newborn sickle cell disease screening tests conducted.
- ✓ 5 clinical care and 6 support care guidance documents, created and adapted for local use.

Post-SCI Preparedness

- ! **Risks/challenges:** Continued government engagement needs to be monitored.
- ✓ **Enabling:** Strong foundation & interest from the business community to support the post-SCI phase.
- ➜ **Priority activities:** Governance, government engagement, donor engagement and financial model, iterative monitoring and evaluation.

Evaluation Conclusions

- ✓ **Relevance:** SCI has been relevant.
- ✓ **Effective:** SCI has been effective.
- ✓ **Efficiency:** SCI is efficient - Note:
  - Continued advocacy to remove local system-level barriers for nurses will maximize their potential.
- ✓ **Coherent:** SCI is coherent - Note:
  - SCI has been coherent internally & externally.
  - Evaluation did not include a comprehensive review of SCI external partnerships.
- ✓ **Sustainability:** There are positive indicators. Note:
  - *Doing well with:* Partnerships, Regional Collaboration, Local ownership, Communication, and Adaptability.
  - *Remains to be seen:* Governance and financial model for the post-SCI phase.

Note: All numbers listed here are anticipated to increase by project end.

1. Introduction & Evaluation Purpose

In the Caribbean, children with cancer or blood disorders are at a particular disadvantage because of limited access to health care workers with specialized training, a shortage of front-line health care providers, limited access to specialized diagnostic services that would enable timely diagnoses, and sparse data on treatment efficacy and disease epidemiology. The risk of poor clinical outcomes is exacerbated by the fact that some of these countries face economic challenges, as well as limited access to certain medicines. SickKids-Caribbean Initiative (SCI) was created in 2013 to help address these challenges by building sustainable local capacity to accurately diagnose, treat, and manage paediatric cancers and blood disorders in the region (SCI Progress Reports, 2014-2020).

SCI is a partnership between The Centre for Global Child Health at The Hospital for Sick Children (SickKids), The University of the West Indies (UWI), Ministries of Health, and hospitals in six Caribbean countries: The Bahamas (Princess Margaret Hospital), Barbados (Queen Elizabeth Hospital), Jamaica (the University Hospital of the West Indies and Bustamante Hospital for Children), St. Lucia (Victoria Hospital), St. Vincent and the Grenadines (Milton Cato Memorial Hospital), and Trinidad and Tobago (Eric Williams Medical Sciences Complex).

The six SCI partner countries have different characteristics and levels of resources available. Appendix 1 summarizes the paediatric population size and health finance mechanisms in each of the six SCI partner countries.

SCI's ultimate goal is to improve the outcomes and quality of life for children with cancer and blood disorders in the Caribbean (Figure 1, SCI Logic Model). To date, SCI has been measuring its progress towards this goal using quantitative monitoring data collected quarterly and a qualitative mid-term project evaluation in 2016. The results were used to inform continuous quality improvement. This year, SCI has commissioned Vitus Research & Evaluation Consulting to conduct another independent evaluation to inform continuous quality improvement and the transition to the post-SCI phase.

The purpose of this evaluation is to answer the following three key questions:

1. What have been the most important outcomes of SCI to date?

2. Within its current structure, scope, and resources, are SCI activities meeting the needs they have been designed to meet in the region?

3. Has SCI been effectively preparing for the post-SCI phase?

Figure 1: SickKids-Caribbean Initiative Logic Mode

Title	SickKids-Caribbean Initiative (SCI)					Duration	8 Years (2013 - 2021)	Funding Agency	SickKids Foundation
Countries	The Bahamas, Barbados, Jamaica, St. Lucia, St. Vincent and the Grenadines, Trinidad and Tobago					Medical Director	Dr. Victor Blanchette		
Primary Stakeholders	Caribbean Hospitals, Ministries of Heath, Regional/Public Health Authorities, SickKids Foundation, The Hospital for Sick Children, The University of the West Indies								

GOAL	Improved outcomes and quality of life for children with cancer and blood disorders in the Caribbean

INTERMEDIATE OUTCOMES	Increased equitable access to specialized paediatric haematology/oncology care across the region	Improved clinical expertise to diagnose and manage paediatric haematology/oncology patients	Increased regional capacity to provide paediatric haematology/oncology care through a community of practice

IMMEDIATE OUTCOMES	Increased utilization of specialized knowledge and skills in patient management	Increased use of data and evidence-based practice to improve clinical care and decision-making	Increased translation and dissemination of evidence based knowledge

PHASE 2 OUTPUTS	Delivery of telemedicine education	Trained haematology/ oncology specialists	Trained haematology/ oncology nurses	Facility-based training/QI initiatives delivered	Participation of SCI-partners in specialist meetings, conferences, and courses	Private case consultations	Public case consultation rounds	Immunophenotyping and minimal residual disease testing provided	Regular analysis and dissemination of data	Development of evidence-based work plans	Publications and presentations	Drug availability and access publication and knowledge translation	Regular engagement of advocacy groups in the region

PHASE 2 ACTIVITIES	Telemedicine education sessions	Support of haematology/ oncology training at SickKids	Support of a third cohort of the SickKids-UWISoN Paediatric Haematology/ Oncology Nursing Education Program	Design and implementation of facility-based training/QI initiatives	Facilitate participation in specialist meetings, conferences, and courses	Private case consultations	Public case consultation rounds	Support for immunophenotyping and minimal residual disease testing	Ongoing collection of oncology data within databases	Annual work planning meeting to review data	Develop and deliver research, knowledge translation, and evaluation activities	Collaboration with PERCC and regional stakeholders on drug availability and access study	Ongoing support for advocacy activities in the region

PHASE 2 FOCUS AREAS	Education	Case Consultations	Local Oncology Databases	Research, Policy and Advocacy

PHASE 2 INPUTS	Stakeholders	Funding	Telemedicine Facilities & Network	MoUs & Agreements	Formalized Partnerships

Transition Advisory Group

2. Background & the Situation at Baseline

2.1. Funding and the Phases of the Intervention

SickKids Foundation provides funding to SCI through private donors and corporations. During Phase 1, which ran from 2013 to early 2018, six working groups guided the implementation of SCI: Clinical Care; Diagnostic Services; Local Oncology Databases; Nursing; Sickle Cell Disease; and Research, Scholarly Activities, and Advocacy. The groups were made up of a cross-section of individuals from the Caribbean sites and SickKids.

As the intervention matured, SCI moved from a foundation-building approach to one that aimed to support and further advance its accomplishments; Phase 2 of SCI launched in April 2018 and while SCI's priorities remained the same, the Phase 1 working groups were revamped into consolidated advisory committees based on the following focus areas:

- Education and Quality Improvement (committee scope includes - but not limited to - activities formerly within Sickle Cell Disease and Nursing working groups);
- Case Consultations (committee scope includes - but not limited to - activities formerly within Clinical Care and Diagnostic Services working groups);
- Local Oncology Databases; and

- Research, Policy, and Advocacy.

Phase 2 of SCI was expected to end in March 2021, but that date is likely to be extended due to a slower financial spend because of a variety of factors, including the COVID-19 pandemic (Correspondence with Project Management Team, July 2020).

2.2 SCI Focus Areas

Unless otherwise stated, the information in this section has been taken from SCI Progress Reports issued from 2014 to 2020 .

2.2.1. Education and Quality Improvement

SCI has developed and delivered a range of education and quality improvement activities including:

- **Support for paediatric haematology/ oncology fellowships** at SickKids. Before this training, there were only three physicians with specialized paediatric haematology/oncology training in the SCI partner countries: one in Barbados, one in The Bahamas, and one in Trinidad and Tobago (Table 1).

- **An accredited one-year paediatric haematology/oncology nursing education program** at the University of the West Indies School of Nursing (UWISoN) at St. Augustine Campus in Trinidad and Tobago. This program was developed and delivered in Phase 1 to build nursing capacity in the field. In

2. Background & the Situation at Baseline

Phase 2, SCI is focusing on educating the third cohort of nursing students and providing further training for nurse graduates through virtual and in-person means.

- **Telemedicine education rounds** on key subjects relevant to the needs in the Caribbean region. At baseline, only Trinidad had a telemedicine facility and SCI invested in six telemedicine videoconferencing facilities for the other five partner countries (including two in Jamaica). The audience for these sessions includes physicians, nurses, surgeons, and laboratory technicians (see Adle *et al.* 2015). Sessions are recorded for future viewing.

- **Country/site-specific education and quality improvement activities**, one to two weeks long, delivered by SickKids nurse educators, physicians, and allied health professionals, and targeting the specific needs of a country or facility.

- **Funded membership in t**he American Society for Paediatric Hematology/ Oncology (ASPHO) and **participation in meetings, conferences, and courses**, including those of the American Society of Hematology (ASH), the International Society of Paediatric Oncology (SIOP), The Caribbean Network of Researchers on Sickle Cell Disease (CAREST), The

Caribbean Nurses Organization, and the Global Sickle Cell Disease Congress.

- The development of localized, context-specific **patient and family education materials,** led by nurses.

2.2.2. Case Consultations

SCI **case consultations** allow Caribbean physicians to access diagnostic testing and expertise that would otherwise not be available. Caribbean physicians discuss difficult cases with SickKids physicians and collaborate to make a timely, accurate diagnosis and plan and adjust treatment as necessary. The cases are also discussed as part of interactive educational sessions, allowing a broader audience to learn about best practices more generally. An important component of case consultations has been the development of five clinical care and six supportive care **guidance documents** - evidence-based, context-specific, and locally owned documents that were made to assist the specialists in providing the best possible care for children.

In tandem with case consultations, SCI facilitates **access to essential cancer and blood disorder testing** for all children from SCI partner sites. SCI has focused on increasing access to flow cytometry for SCI partner countries so that immunopheno-typing can be used to identify leukemia and

lymphoma, which together make up 40% of all paediatric cancers.

At baseline (Table 2), Jamaica was the only country in the region that had locally available immunophenotyping testing capability (through the University Hospital of the West Indies), but there was a cost associated with these tests for the families. SCI also works towards increasing newborn sickle cell disease screening and treatment for children who have the disease because relevant local resources are scarce despite sickle cell disease being the most common genetic disorder in the Caribbean (Odame, 2014; Knight-Madden *et al.*, 2019). If left untreated, this disease can result in painful crises, strokes, infection, and early mortality.

Through SCI, four SCI partner countries (Barbados, The Bahamas, Jamaica, and Trinidad & Tobago) were invited to participate in **the Children's International Consortium for Acute Leukemia Initiative (C-ICAL)**, an international network established by The American Society of Hematology (ASH). C-ICAL seeks to improve the care of children with acute lymphoblastic leukemia (ALL) – the most common cancer affecting children, by establishing a common treatment protocol, and together with SCI is supporting key diagnostics, and monitoring results through a dedicated and supported database.

2. Background & the Situation at Baseline

2.2.3. Local Oncology Databases

SCI has developed seven **local hospital-based oncology databases**, with two located in Jamaica and one in each of the other partner countries. Such databases did not exist before SCI, which made it impossible to monitor the incidence, treatment, and outcomes of paediatric oncology patients. Seven database managers trained by SCI conduct retrospective and prospective data collection and entry to inform the work of SCI partners.

2.2.4. Research, Policy, and Advocacy

Through the **Research, Policy and Advocacy** focus area, SCI aims to investigate and advocate for the needs of children with cancer and blood disorders. For example:

- A **drug availability and access study** has been conducted in partnership with SickKids Hospital's Policy and Economic Research in Childhood Cancer (PERCC), seeking to improve understanding of challenges related to childhood cancer and sickle cell disease drug access in the Caribbean region.
- Four SCI partner countries are members of the Pan American Health Organization

(PAHO) Childhood Cancer Working Group for Latin America and the Caribbean. 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.

- SCI works with the Caribbean Network of Researchers on Sickle Cell Disease (CAREST), the Caribbean Institute for Health Research (CAIHR), and civil society groups to promote awareness about the disease and advocate for evidence-based diagnosis and care for children with sickle cell disease.

Table 1: SCI partner countries had varying levels of resources available to them at baseline (2013).						
	The Bahamas	Barbados	Jamaica	St. Lucia	St. Vincent & the Grenadines	Trinidad & Tobago
No. of paediatric haematologists/ oncologists.	1	1	0	0	0	1
No. of nurses with specialized paediatric haematology/ oncology training	0	0	0	0	0	0
Number of specialist children's hospitals	0	0	1[a]	0	0	1[a]
Local Immunophenotyping (flow cytometry) diagnostics services	No	No	Yes[b]	No	No	No
% of infants screened for sickle cell disease	See note c	See note c	>43% <100%[d]	100	See note c	See note c
Telemedicine facilities	0	0	0	0	0	1
Hospital-based paediatric oncology database	0	0	0	0	0	0
Notes: a) Bustamante Hospital for Children (Jamaica); The Wendy Fitzwilliams Paediatric Hospital (Trinidad & Tobago) b) At the University Hospital of the West Indies , a private hospital. c) Country-specific data could not be found but it is estimated that only 50% of the English- and Spanish-speaking infants are screened in the Caribbean (Knight-Madden et al., 2019). d) Before 2008, it was estimated that 43% of Jamaican newborns received sickle cell disease screening, by 2015, Jamaica had achieved universal newborn screening (Knight-Madden et al., 2019). Sources: SCI Progress Reports 2013-2019; Meetings with SCI project management team.						

3. Methodology & Participants

3.1 Key Evaluation Questions

The key evaluation questions considered in this report are:

1. What have been the most important outcomes of SCI to date?
2. Within its current structure, scope, and resources, are SCI activities meeting the needs they have been designed to meet in the region?
3. Has SCI been effectively preparing for the post-SCI phase?

3.2 Evaluation Design & Sources

The following sources were used to answer the three key evaluation questions :

- Individual interviews with SCI partners conducted in June 2020 (n=17) (see Appendix 2 for Interview Guide);
- Surveys collected from SCI partners in June 2020 (n=17) (see Appendix 3 for Survey Instrument and modification to data collection strategy due to COVID-19 pandemic);
- Meetings and correspondence with SCI project management team;
- SCI documents, including logic models, progress reports (2014-2020), meeting minutes, mid-term evaluation report, SCI newsletters; and
- Relevant research and evaluation literature.

3.3 Sampling Approach

Survey participants and interviewees for this evaluation were selected through purposeful sampling, a kind of nonprobability sampling where study participants are chosen according to the investigator's criteria, rather than randomly. Purposeful sampling allows researchers to solicit the desired information from the informants most able to provide it (Patton, 1990). Purposeful sampling is often preferred in qualitative studies when the sample must be contained due to resource constraints. Two criteria were used:

1. *Maximum variation.* This sampling technique ensures that perspectives are heard from a wide variety of stakeholders (Patton, 2001). Accordingly, the sample included diverse roles and countries (see Section 3.6).

2. *Politically important cases.* Within the variation described above, priority was given to individuals who are particularly influential in or knowledgeable about SCI. Politically important cases sampling ensures that the credibility of the evaluation results is not jeopardized by the conspicuous non-participation of important individuals (Patton, 1990).

3. Methodology & Participants

3.4 Analytical and Reporting Approach

A contribution analysis method was used to validate SCI's logic model (Mayne, 2012; Vaessen, 2012;). By using independently gathered and analyzed data to reconstruct the logic of the program, this method can assess if, how, and to what extent SCI activities listed on the model contribute to its ultimate goal. This technique allows for the identification of risks and strengths behind the links shown on the logic model and can uncover details behind the pathways through which outcomes are achieved. Interviews and survey data were coded both inductively, allowing novel ideas to emerge from the data, and deductively, by looking for specific pieces of information according to a pre-determined codebook developed based on document and literature review (Boyatzis, 1998; Nowell, 2017).

For the purposes of reporting the results, and informed by Hannah & Lautsh's recommendations (2011) this evaluation consultant takes the following approach:

- If counting the answers on their own produced a significant and useful finding, the number of responses is presented.

- If counting the answers did not add to the analysis or risked the confidentiality of the respondents, words such as "a few", "some" and "many" are used and

are intentionally left imprecise (see Maxwell, 2010 for more details).

Unless otherwise stated, all the monitoring data cited in this report are from 2013 until March 31, 2020 (SCI Dashboard, 2020).

3.5 Evaluation Criteria

The following evaluation criteria (OECD, 2019) were used for making conclusions about the findings:

- **Relevance:** The extent to which the intervention objectives and design respond to beneficiaries' needs, policies, and priorities, and would continue to do so if circumstances change.

- **Effectiveness:** The extent to which the intervention achieved, or is expected to achieve, its objectives, including any differential results across groups.

- **Coherence**: The compatibility of the component activities of the intervention, and the compatibility of the intervention with other related interventions.

- **Efficiency:** The extent to which the intervention delivers, or is likely to deliver, results in an economical and timely way.

- **Sustainability:** The extent to which the net benefits of the intervention continue or are likely to continue (for more information on the key factors that influence sustainability of global health

programs in transition, see Appendix 4).

3.6 Participants

In total, 34 individuals participated in this study. The participation rate for the interviews was 100% (17 out of 17 invited) and for the surveys was 80% (17 out of 21). Participants included:

- 15 Caribbean physicians
- 13 SickKids physicians
- 5 Members of the project management team
- 4 Caribbean nurses
- 2 SickKids nurses
- 1 Caribbean/SickKids physician (fellow)
- 1 Project management team member/SickKids nurse

Geographic diversity of respondents:

- Canada (15)
- Jamaica (8)
- Trinidad (6)
- Barbados (2)
- St. Vincent & the Grenadines (1)
- The Bahamas (1)
- St. Lucia (1)

4. Key Findings

4.1 Key Evaluation Question 1: What are the Most Important Outcomes of SCI to date?

This section describes the multiple important outcomes mentioned by participants and uncovered through document review. Three outcome pathways (A,B, and C) have been visualized to assist the reader in understanding the nuances and interrelationships between the outcomes, and also the subjective experience of the outcomes in the words of the participants.

The three most important outcomes associated with SCI reported by study participants were:

A. SCI has increased the number of physicians and nurses in the region who specialize in paediatric haematology/oncology, helping to fill a large human resource gap.

B. By enhancing the capacity of health providers, SCI has contributed to improved diagnosis, treatment, and management of paediatric haematology/oncology patients

C. SCI's community of practice has increased the region's capacity to provide paediatric haematology/ oncology care

Each of these outcomes is examined in detail.

4.1.1 SCI has Increased Number of Physicians and Nurses in the Region who Specialize in Paediatric Haematology/Oncology, Helping to Fill a Large Human Resource Gap.

Before SCI (2013), there were only three paediatric haematologists/oncologist in SCI partner countries and no specialist paediatric haematology/ oncology nurses. As of July 2020, a total of four additional paediatric haematology/oncology physicians and 27 paediatric haematology/oncology nurses in these countries have been trained. Another physician will start her training later in 2020 (delayed due to COVID-19) and another 14 nurses will finish their training in November 2020, with official graduation in January 2021 (also delayed due to COVID-19). This will take the total to seven paediatric haematology/oncology physicians and 40 paediatric haematology/oncology nurses (see Figure 2). SCI has sponsored the training of all the physicians and nurses with the exception of one nurse who was locally sponsored.

Participants said that the increased number of haematology/oncology physicians and nurses were the prerequisites to achieving all other outcomes and described how the existence of this cadre has contributed to the improved diagnosis, treatment and management of paediatric haematology/ oncology patients (see Figure 3, Pathway A).

Figure 2: Distribution of paediatric haematology/oncology physicians and nurses, and oncology database managers before SCI and at present (July 2020). One more fellow will start a haematology/oncology fellowship at SickKids later in 2020 (delayed due to COVID-19 pandemic). The number of nurses includes cohorts 1,2 (both already graduated), and 3 (graduation has been delayed due to COVID-19 pandemic but expected to be November 2020). Two nurse graduates are also database managers (shown with a distinct icon). One of the nurses included here was locally sponsored.
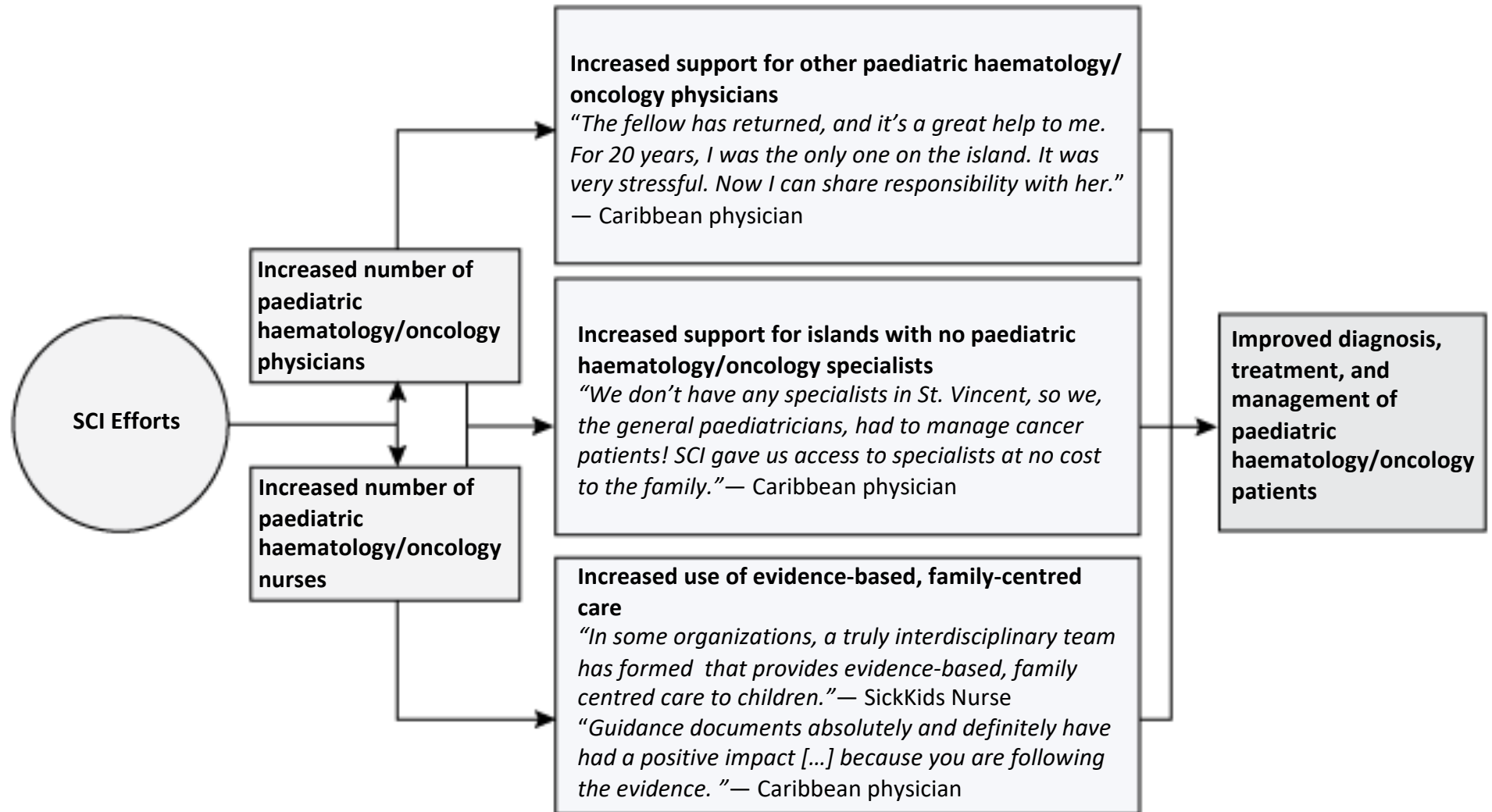*Sources: SCI Records.*
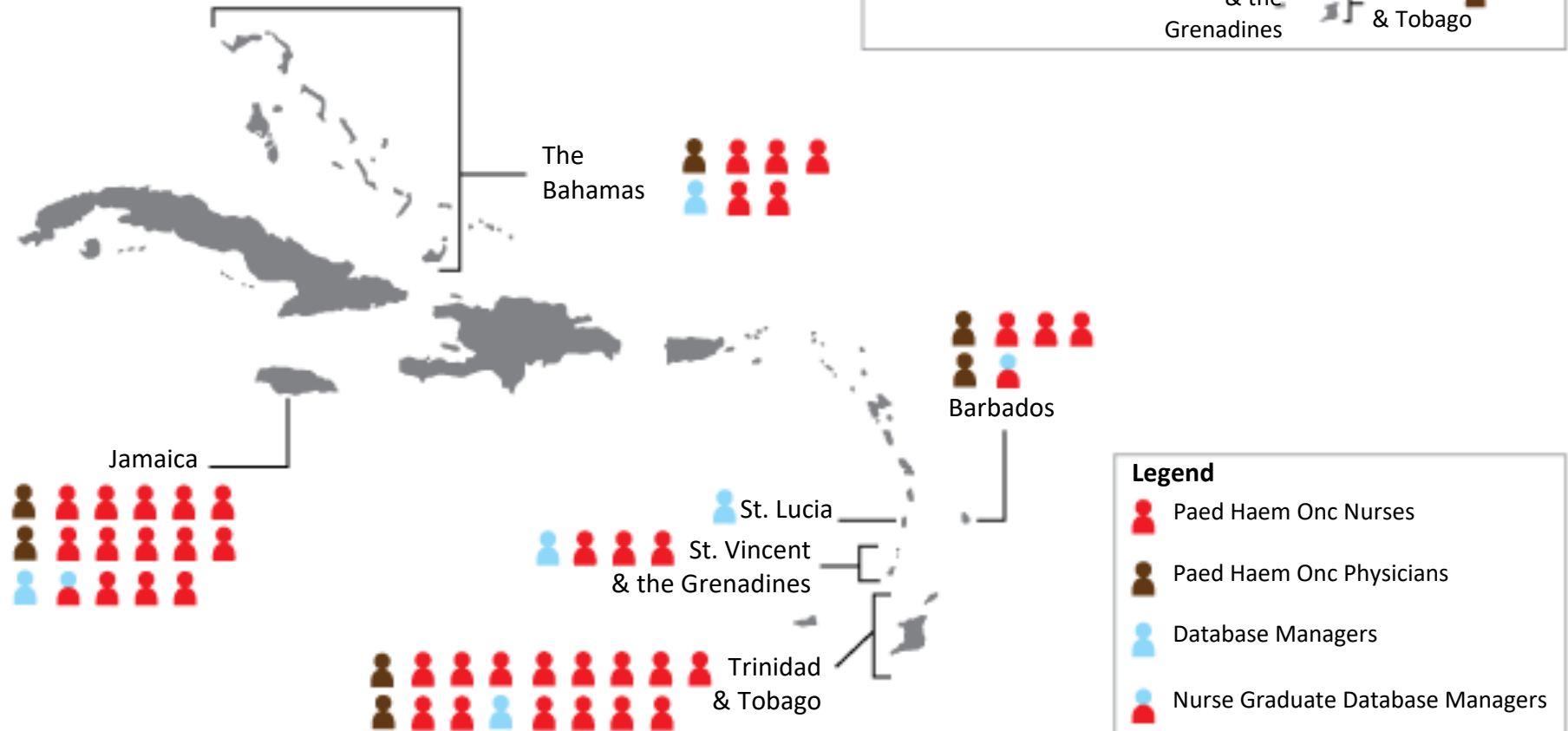
4. Key Findings: Question 1

Figure 3: *Pathway A* illustrates how the increased number of haematology/oncology physicians and nurses has contributed to improved diagnosis, treatment, and management of patients.

SCI Efforts

Increased number of paediatric haematology/oncology physicians

Increased number of paediatric haematology/oncology nurses

Increased support for other paediatric haematology/oncology physicians
"The fellow has returned, and it's a great help to me. For 20 years, I was the only one on the island. It was very stressful. Now I can share responsibility with her."
— Caribbean physician

Increased support for islands with no paediatric haematology/oncology specialists
"We don't have any specialists in St. Vincent, so we, the general paediatricians, had to manage cancer patients! SCI gave us access to specialists at no cost to the family."— Caribbean physician

Increased use of evidence-based, family-centred care
"In some organizations, a truly interdisciplinary team has formed that provides evidence-based, family centred care to children."— SickKids Nurse
"Guidance documents absolutely and definitely have had a positive impact […] because you are following the evidence. "— Caribbean physician

Improved diagnosis, treatment, and management of paediatric haematology/oncology patients

4. Key Findings: Question 1

Paediatric Haematology/Oncology Nurses

The SCI-trained nurses are making an "invaluable" contribution to patient care by applying their newly acquired skills at the bedside and leading initiatives to improve patient care. The Caribbean physicians who were interviewed, as well as nurses both at SickKids and the Caribbean sites, said the nurses are "doing great," and that having their expertise in health facilities is fundamental to caring for patients. Examples of nurse-led activities included implementing quality improvement initiatives for safe handling of chemotherapy drugs, creating patient education material, and creating a nurse-led haematology clinic in collaboration with a haematologist in Trinidad.

Investing in nurses was referred to as "smart" and "sustainable." In light of the "severe brain drain from the region," the fact that 96% (26 out of 27) of graduates have so far remained in the region (Annual Work Planning Meeting, 2019 Meeting Summary) is welcome news for the project.

> "Nurses? That's huge! I can't even say how much. This work requires interprofessional collaboration, we have several graduates here working in my hospital, it's a huge help." —Caribbean physician

> "Their scope of practice has broadened in many organizations. They are sharing their knowledge formally and informally, and in some organizations, a truly interdisciplinary team has formed that provides evidence-based, family-centred care to children; for example, the oncology team in The Bahamas and haematology team in Trinidad." —SickKids nurse

Paediatric Haematology/ Oncology Physicians

Not only are there more specialist physicians in the region as a result of SCI's efforts, but they are connected and actively collaborate with a unified goal to improve patient care for children with cancer and blood disorders in the region. This new generation of specialists has also meant that those islands that still do not have a specialist have increased options in terms of seeking support for their patients from a regional specialist.

> "We knew each other before SCI, but we never talked […] We have a bond now, a common goal."—Caribbean physician

4.1.2 By Enhancing the Capacity of Health Providers, SCI has Contributed to Improved Diagnosis, Treatment, and Management of Paediatric Haematology/Oncology Patients
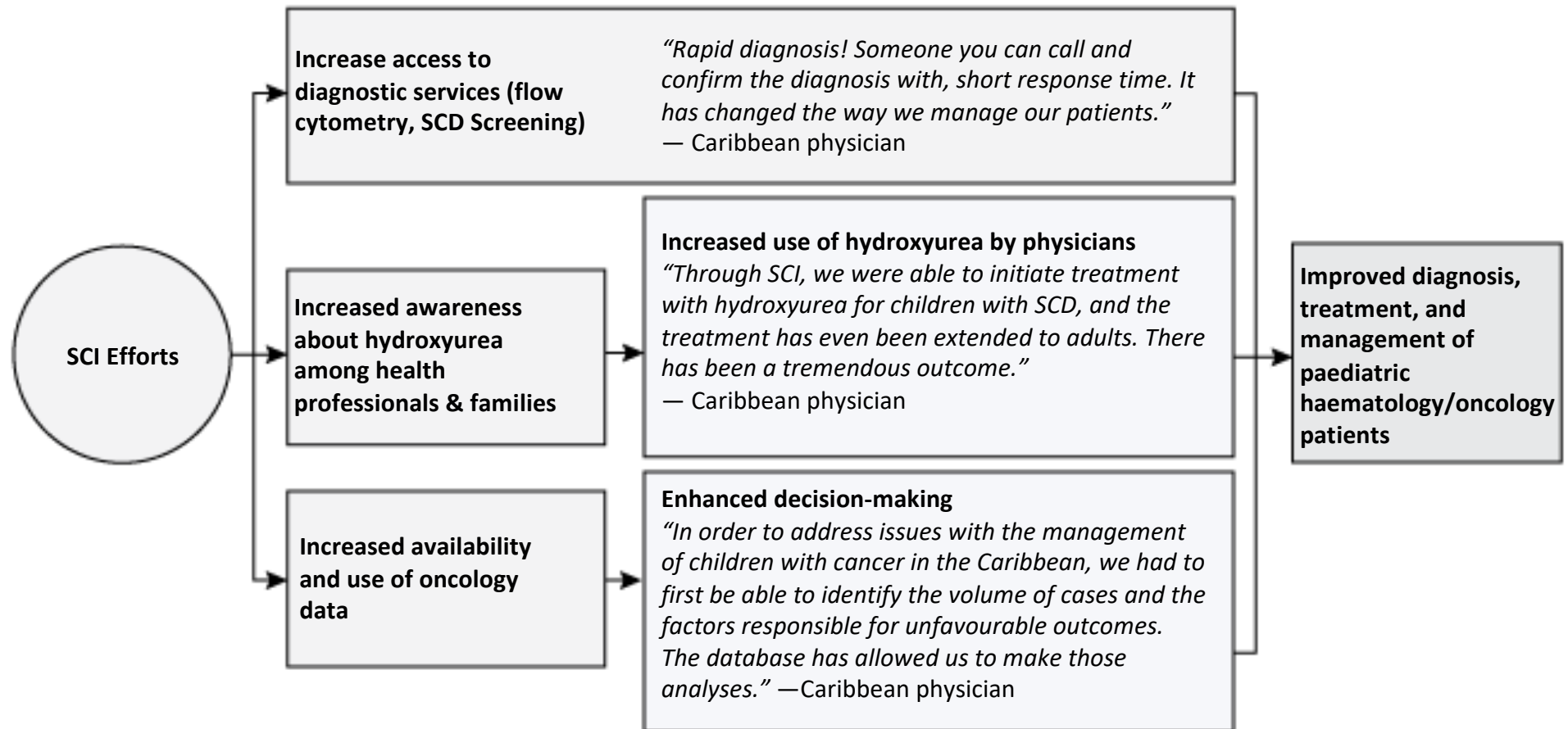
Participants discussed how the haematology/oncology cadre was empowered to improve patient care through better access to diagnostic services, the availability of oncology data, and SCI's efforts to raise awareness about sickle cell disease (see Figure 4, Pathway B).

Case Consultations

Case consultations was one of the most passionately discussed activities. To date, more than 510 cases have been submitted to SickKids physicians for consultation. Participants said the ability to discuss cases with SickKids specialists, and to ask for a second opinion, has made "a huge difference" for their patients and has decreased the physicians' sense of isolation because "it's so hard not having someone else to bounce ideas off when you are the only specialist in the country." The consultations were described as timely and culturally appropriate, and the Caribbean physicians appreciated that available local options were considered.

4. Key Findings: Question 1

Figure 4: *Pathway B* illustrates how the haematology/oncology cadre was empowered to better diagnose, treat, and manage patients by improved access to diagnostic services, the availability of oncology data, and increased awareness about sickle cell disease treatment.

SCI Efforts

Increase access to diagnostic services (flow cytometry, SCD Screening)

"Rapid diagnosis! Someone you can call and confirm the diagnosis with, short response time. It has changed the way we manage our patients."
— Caribbean physician

Increased awareness about hydroxyurea among health professionals & families

Increased use of hydroxyurea by physicians
"Through SCI, we were able to initiate treatment with hydroxyurea for children with SCD, and the treatment has even been extended to adults. There has been a tremendous outcome."
— Caribbean physician

Increased availability and use of oncology data

Enhanced decision-making
"In order to address issues with the management of children with cancer in the Caribbean, we had to first be able to identify the volume of cases and the factors responsible for unfavourable outcomes. The database has allowed us to make those analyses." —Caribbean physician

Improved diagnosis, treatment, and management of paediatric haematology/oncology patients

4. Key Findings: Question 1

> *"[Case consultation] makes a huge difference in patient outcomes. It has happened to me several times, when you ask for a test, and ask for a second opinion because some cancers might look like another. That I could do that, has made a huge difference for my patients."* — Caribbean physician

Access to Diagnostic Technology and Pathology Expertise

Access to diagnostic technology and expertise was also frequently mentioned as a fundamental prerequisite to improving outcomes for children with cancer and blood disorders, because, as one Caribbean physician said: *"Without diagnosis, it's like walking in the dark."*

As Table 1 showed, before SCI, the University Hospital of the West Indies (UHWI) was the only site in SCI partner countries that had flow cytometry testing capability, and there was a cost associated with the service. During Phase 1, SCI made flow cytometry through UHWI free for all patients in Jamaica and provides free flow cytometry, conducted at SickKids, for the other five partner countries. SCI also made it possible for all SCI partner countries to send samples to SickKids Hospital for minimal residual disease testing, another cancer diagnostic test unavailable locally. To date, over 330 diagnostic tests for patients

with leukemia have been conducted (the number is comprised of immuno-phenotyping testing at SickKids and the University Hospital in Jamaica, and minimal residual disease testing at SickKids). 142 of the cases submitted to SickKids required diagnostic imaging and 167 needed pathology expertise.

SCI has contributed to increased access to sickle cell disease screening in some parts of the Caribbean. To date, 93,868 newborn sickle cell disease screening tests have been conducted for newborns in Jamaica and St. Lucia (note that the time period for the St. Lucia newborn screening pilot was from 2015-2018). SCI has funded a nurse in Jamaica to help roll out newborn screening in Jamaica. These newborn screening tests were perceived as extremely important because, as one Caribbean physician observed, *"the sooner you can diagnose the baby, the sooner you can prevent all the devastating outcomes associated with this disease as the child grows up."*

As of 2015, Jamaica has universal SCD screening (Knight-Madden *et al*., 2019) thanks to the efforts of various groups, including the Caribbean Institute for Health Research and SCI.

SCI efforts through quality improvement initiatives and education sessions to build awareness and debunk myths about

hydroxyurea – an effective but underused drug (Mburu & Odame, 2019) – has led to increased use of the drug and enhanced patient management, according to the interviewees.

> *" I have changed the way I counsel my patients about hydroxyurea after observing [SickKids physician]. I used to ask, did you take your medication and they would say yes. He would sit close, look them in the eye, gently ask: 'tell me, tell me *how many* pills did you take last week? We all forget things.' And they say: 'Well, on Monday I forgot.' So you get the real answer."* —Caribbean physician

Data Derived from the Local Oncology Database

To date, 687 patients' data have been registered in the local oncology databases and data are analyzed and discussed in annual planning meetings. The databases and the database managers who were trained to use them were described as having played a *"critical role"* in improve-ments in patient care and outcomes. Participating physicians mentioned the emergence of data that accurately document outcomes of patients over time as having improved their decision-making. As one Caribbean physician put it, *"You can go back to cases and see the details, the outcomes, see what happened."*

4. Key Findings: Question 1

A concrete example of how the data from the oncology databases have led to improved decision-making and improved patient outcomes is when the data revealed the need to form the acute myeloid leukemia (AML) consulting subgroup to facilitate timely consultation when cases of this high-risk disease present themselves. Since its inception in September 2019, encouraging results have been seen in lowering the rate of early treatment mortality. Stakeholders acknowledged that these are early results and progress needs to be monitored (Annual Work Planning Meeting, 2019 Meeting Summary).

4.1.3 SCI's Community of Practice has Increased Region's Capacity to Provide Haematology/Oncology Care

The participants said that SCI has transformed what used to be a few specialists working in silos in the region into a community of practice. Upon further probing, they were able to articulate the attributes of this community of practice (Wenger-Trayner, 2015) and identify the outcomes that it has led to, as discussed below and shown in Pathway C (Figure 5).

The core members of this community consist of the Caribbean physicians and nurses affiliated with SCI, as well as SickKids physicians and nurses, and the program management team. There is a high degree of trust and mutual admiration among these members. Words such as "*family*," "*friendship*," "*camaraderie*," "*transparency*," "*trust*," and "*respect*" were used in abundance to describe the quality of the network that has formed between the members (see Appendix 5, SCI in the Words of the Participants). Members identify with and are passionate about a clear goal: improving diagnosis, care, and treatment for all the children in the region who suffer from cancer or blood disorders. Members meet annually, for ad hoc case consultations, and more formal rounds, advisory committee meetings, and education sessions. Meetings are sometimes in person, but online platforms (especially Zoom) are used to facilitate these meetings, whether members are in telemedicine facilities, or in their own offices or homes. Communication from SickKids to other members was perceived as "*clear*" and "*transparent.*"

Over time, this core group has been able to make connections with several key international organizations and groups, such as the Pan American Health Organization (PAHO) Childhood Cancer Working Group for Latin America and the Caribbean (see Section 2.2.4) and the American Society of Hematology (ASH), as discussed in Section 2.2.2, regarding the International Consortium for Acute Leukemia Initiative (C-ICAL). SCI's involvement in the C-ICAL initiative was described as "*an unexpected winner*" and the outcomes associated with it included increased international exposure, implementation of a locally relevant clinical protocol for treating children with acute lymphoblastic leukemia in SCI countries, and increased capacity for a clinical network in the region.

The attributes listed above have enabled the community of practice to achieve several outcomes, shown in Figure 5, namely:
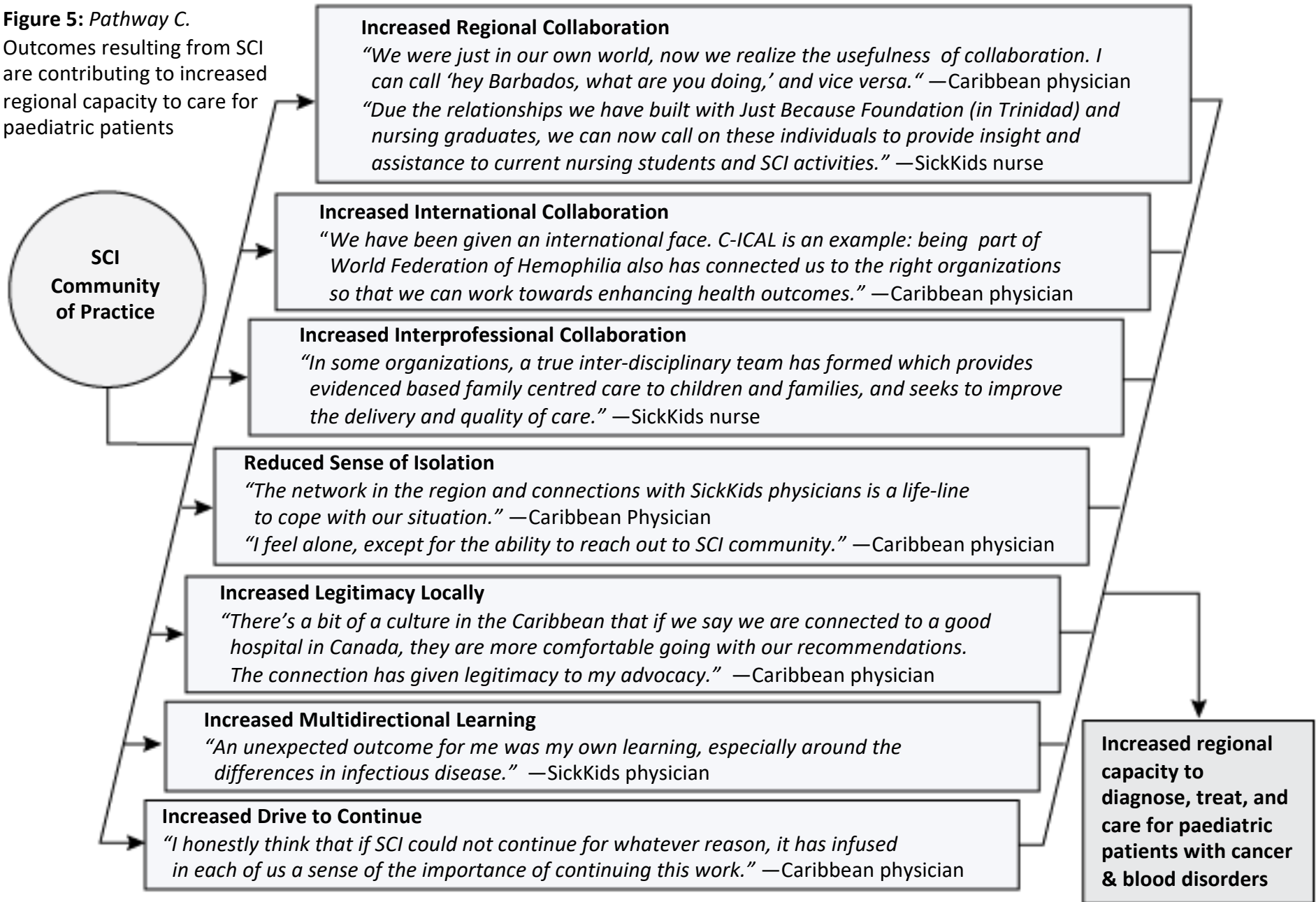
- Increased collaboration (regional, international, and interpersonal),
- A reduced sense of isolation for Caribbean nurses and physicians,
- Increased legitimacy of the Caribbean physicians and nurses locally,
- Increased multi-directional learning for all members, and
- Increased drive to continue with the community of practice's goal despite the challenges faced.

These outcomes, taken together, ultimately lead to the increased regional capacity to provide paediatric haematology/oncology care.

4. Key Findings: Question 1

Figure 5: *Pathway C.*
Outcomes resulting from SCI are contributing to increased regional capacity to care for paediatric patients

SCI Community of Practice

Increased Regional Collaboration
"We were just in our own world, now we realize the usefulness of collaboration. I can call 'hey Barbados, what are you doing,' and vice versa." —Caribbean physician
"Due the relationships we have built with Just Because Foundation (in Trinidad) and nursing graduates, we can now call on these individuals to provide insight and assistance to current nursing students and SCI activities." —SickKids nurse

Increased International Collaboration
"We have been given an international face. C-ICAL is an example: being part of World Federation of Hemophilia also has connected us to the right organizations so that we can work towards enhancing health outcomes." —Caribbean physician

Increased Interprofessional Collaboration
"In some organizations, a true inter-disciplinary team has formed which provides evidenced based family centred care to children and families, and seeks to improve the delivery and quality of care." —SickKids nurse

Reduced Sense of Isolation
"The network in the region and connections with SickKids physicians is a life-line to cope with our situation." —Caribbean Physician
"I feel alone, except for the ability to reach out to SCI community." —Caribbean physician

Increased Legitimacy Locally
"There's a bit of a culture in the Caribbean that if we say we are connected to a good hospital in Canada, they are more comfortable going with our recommendations. The connection has given legitimacy to my advocacy." —Caribbean physician

Increased Multidirectional Learning
"An unexpected outcome for me was my own learning, especially around the differences in infectious disease." —SickKids physician

Increased Drive to Continue
"I honestly think that if SCI could not continue for whatever reason, it has infused in each of us a sense of the importance of continuing this work." —Caribbean physician

Increased regional capacity to diagnose, treat, and care for paediatric patients with cancer & blood disorders

4. Key Findings: Question 1

4.1.4 Other Outcomes

The following additional outcomes were also mentioned in passing or were uncovered through document review:

1. Improving capacity in health professionals other than nurses and doctors. Participants said several laboratory technicians had been trained by SCI and that telemedicine sessions were benefiting a broad range of health professionals. Consultation with SickKids pharmacy was cited as another example of capacity building, SickKids pharmacists had assisted their Caribbean colleagues with creating necessary treatment compounds.

2. The Children's International Consortium for Acute Leukemia (C-ICAL) initiative provides participating Caribbean physicians access to additional expertise with which to consult in treating children with acute lymphoblastic leukemia (ALL) in their countries.

3. Improved capacity in nurses and physicians who were not directly trained by SCI by those who were. Nurses were reported to be teaching "*even the interns*" and other nurses who they work with.

4. Improved regional awareness about children with cancer and blood disorders.

5. A Caribbean physician mentioned "*Networking with other groups outside of SCI because of an initial contact with someone within SCI.*" An example was the connection created through SCI with the organizations that are helping children with haemophilia, a disease that affects a small number of children but without proper management can lead to severe joint deformity and disability.

6. The development of telemedicine sites as essential infrastructure that has also made many other activities possible.

7. Two Caribbean physicians mentioned that they see early signs that survival rates of patients are increasing in their hospitals. More data is needed to effectively showcase this important outcome.

"*Haemophilia patients have not had a good run in their care until now. It's a big change to have this recognition. There are other organizations that we work on this issue, the World Haemophilia and Novo Nordisk Haemophilia Foundation, but I would say, we came to be recognized by these groups because of SCI.*" —Caribbean physician

4.2 Key Evaluation Question 2: Within its current structure, scope, and resources, are SCI activities meeting the needs they have been designed to meet in the region?

4.2.1 Focus Area: Education

Overall feedback on **the haematology/ oncology fellowship and nursing education program** was positive. The Caribbean physicians described their experience at SickKids as "*rewarding*" and felt supported by the training program. It was reported that formative evaluation with nurse graduates (through post-program satisfaction surveys) has shown that they are satisfied overall with the training.

Telemedicine sessions were also viewed positively (average overall participant satisfaction out of 5 = 4.15 for 2019-2020, n=179). The use of Zoom was perceived as having increased participation rates because participants can now be anywhere and attend. Zoom sessions are also recorded and can be viewed after the session, which was appreciated by the participants.

> "*It's difficult to find a time that works for everyone, so Zoom has helped. It's great that you can watch it later.*" —Caribbean physician

Both SickKids and the Caribbean partners recognize the importance of **facility-based training and quality improvement initiatives**. The participants in the education and quality improvement sessions held in The Bahamas and Trinidad and Tobago rated the experience very positively and there is evidence that that the participants learned relevant and practical skills (see Appendix 6). **Patient and family education materials** were acknowledged as an "*exciting future area of work*" but one that had only recently commenced, making evaluation premature.

Participation in specialist meetings and conferences has been seen to meet needs around connecting with the global paediatric haematology/oncology community and creating a forum for important conversations. To date, SCI has funded 53 memberships in the American Society of Pediatric Hematology/Oncology (ASPHO), and 56 attendances at special meetings, conferences and courses.

Ways to Better Meet Needs

Nursing
Participants identified several local system-level challenges and opportunities related to the recruitment of nurses and supporting the graduates of the nursing training program. Some nurses have not been able to obtain study leave to participate in this

training program – no one from St. Lucia, for example, has been able to attend despite being offered sponsorship by SCI. Also upon graduation, some nurses are not able to practice their newly gained skills because of limits associated with their scope of practice. Similarly, due to an overall shortage of nurses, some of the graduates have been assigned to administrative duties.

"There are some issues with the scope of practice. It's frustrating for [the graduates], I know SCI has tried to push for this. For example, the ability to administer chemotherapy, they know how to do it, they even teach the interns, but they themselves are not allowed to do it. And the islands are different… In Jamaica, some places nurses can administer chemotherapy, in some places no. In The Bahamas, they can administer. In Trinidad, they can't." — Caribbean nurse

"Two of the four nurse graduates, are assigned to manage patients, but two are assigned as administrators due to shortages, so the senior nurses are not as active in patient care. That's unfortunate because with the rapid turnover and brain drain, there is benefit in having experienced senior nurses [practicing patient care]." — Caribbean physician

While everyone who mentioned these challenges agreed that they are outside the control of SCI or the nursing program, they suggested SCI and the University of the West Indies continue with advocacy and government engagement on behalf of nurses to ensure this valuable workforce can fulfill their potential and better support SCI in reaching its long-term goal.

Finally, some respondents suggested creating a fellowship opportunity for nurses.

"I wish there was a fellowship for nurses so we could observe how things are done at SickKids." —Caribbean nurse

Facility-based training and quality improvement

Despite the success of the delivered quality improvement and education initiatives (see Appendix 6), and their perceived importance, respondents viewed these activities as a work in progress. One Caribbean physician observed, "*they are important, we know, but it's hard with little time and few qualified people to run them.*" A SickKids nurse acknowledged, "*there have been some successes, however, I don't think we have nailed down the formula for engaging partners in initiatives that can be sustained over time.*" Another SickKids nurse stated: "*Some facilities are more able and ready to participate in quality improvement initiatives than others.*" One SickKids nurse suggested that an improved

assessment process would help partners "*to assess how ready they are for change and identifying the supports and resources that are available.*"

4.2.2 Focus Area: Case Consultation

As discussed in Section 4.1.2, **case consultations** were particularly valuable to Caribbean physicians and were said to directly impact patient outcomes. SCI's achievements in making **flow cytometry diagnostic testing** available at no charge to all SCI partner countries and to increase SCD screening in the region were deemed valuable. The **clinical and supportive care guidance documents** were described as "*a part of my daily diet*" and were reported as frequently used by all Caribbean physicians interviewed.

Ways to Better Meet Needs

To further increase access to cancer diagnostic technology in the region, there has been a continued effort from SCI to build capacity at the National Public Health Laboratory (NPHL) in Jamaica to provide a second testing site for flow cytometry. There have been local challenges with stocks of staining reagents necessary for the test. Consequently, flow cytometry tests for Bustamante hospital have had to sometimes occur at the University Hospital of the West Indies and, on occasion, the tests for both hospitals have had to occur at SickKids

(Correspondence with SCI project management team, June 2020). Participants mentioned the need for sustainable access to reagents to address this challenge.

Two physicians advised that holding regularly scheduled **case consultation** rounds on brain tumours are necessary because they are rare and education, repetition, and updates are essential to effective treatment. There was an appetite for creating more **clinical and supportive care guidance documents,** given their critical role in patient care.

"Regular solid tumour and neuro-oncology or combined scheduled rounds for the Caribbean countries. Neuro-oncology expertise is needed as the cases that need consultation are usually advanced in their disease and regular/early discussions will be helpful with overall outcomes. Most solid tumour/ neuro-oncology cases need a multi-team discussion with surgeons (urology/general surgery/orthopedics/ neuro-surgery)" —Caribbean/SickKids physician

4.2.3 Focus Area: Local Oncology Database

The **collection of oncology data** is meeting the needs of the region, as discussed in Section 4.1.2. The participants noted that the **collective review of aggregate data and action planning based on it** has been useful because the number of cases in each

country may be small but when the data are aggregated, they becomes more impactful and allow the group to talk at a regional level about the burden of paediatric cancers. This could lead to more *"bargaining power"* when it comes to purchasing drugs because countries can buy in larger quantities as a syndicate than as individual countries.

Ways to Better Meet Needs

Participants mentioned that if they had full-time research assistants who could not only enter or pull the data but also help with the analysis, country-led research based on oncology data could increase, ensuring that the potential of the database is fully realized.

4.2.4 Focus Area: Research, Policy and Advocacy

Some participants thought that there have been a good number of **research, knowledge translation and evaluation activities**, but others thought there was potential for greater output while acknowledging that it is difficult to coordinate with and meaningfully engage individuals in these activities across six countries. To date, there have been 32 SCI-related presentations in international conferences, five SCI publications, and one mid-term evaluation. Within this set of activities, the participants spoke about the

usefulness of the **drug availability and access study**. The participants said the results (manuscript underway) could help with SCI advocacy efforts to secure essential medicines for treating patients. Participants who had taken **advocacy training** through SCI (either through a workshop or as part of the fellowship training program) found it useful because they have been able to put what they have learned into practice.

"Advocacy training in fellowship met the need. When I returned from my fellowship, I was able to put it into practice. I wrote about SCD in a journal using the skills I had learned, and the audience for the journal was all the doctors in the country, also pharmacists, with the potential [for the article] to be seen by health administrators at the Ministry of Health." —Caribbean physician

The meeting organized by the World Health Organization (WHO) and Pan American Health Organization (PAHO) in February 2020 was described as *"a great starting point to influence health policy"* and *"powerful to sit in."* During this meeting, the aim of which was to discuss strategies to improve childhood cancer care in the region, SCI Caribbean partners and SickKids were invited to participate in joint priority-setting and action planning with representatives from national and regional governments and civil society. The outputs

from the meeting were early drafts of three-to-five-year project plans for country-specific and region-wide activities to strengthen the health system response to childhood cancer. PAHO will coordinate with local leaders and partner organizations on their respective national paediatric cancer plans and the implementation of the region-wide activities (PAHO, 2020). Understanding how the implementation of these plans will contribute to SCI's goal is an important area for future evaluations.

Ways to Better Meet Needs

Participants agreed that now that both the data (e.g. through the oncology database and drug availability and access study) and the right linkages to put the data in front of governments (e.g. PAHO working group) have been created, **research, knowledge translation and evaluation activities** can be even more impactful than other points in the lifecycle of SCI. Suggestions for what to focus on included evaluation of the impact of the nursing education program and an economic analysis of cost-savings related to treatment of children with cancer or blood disorders.

Participants commented that further gains could be achieved concerning sickle cell disease screening if the results of **St. Lucia Pilot** study were made available for discussion, publication, and advocacy. The goal of this pilot was to advocate for greater adoption of the heel-prick method of testing, instead of the cord blood method currently used in St. Lucia, because it is more efficient and accurate. Another goal was to show that sending samples to Jamaica for testing is a cost-effective approach. Several challenges were encountered during this project, including concerns over the cost of switching from one method of testing to another, difficulty adopting to a new way of testing, and change of key personnel involved in the study in St. Lucia.

> *"Heel-prick is used in high-income countries, in lower-income places it's not the culture, and so insisting on it didn't work."* — Caribbean physician

Some participants said more **advocacy-related activities** are needed because advocacy groups usually fill a gap in patient care that is not covered by the government or healthcare services. For example, they help with finding accommodation and provide emotional support for families who need to travel to access care for their child. The Just Because Foundation in Trinidad was mentioned as an example of a pre-existing community group that is filling this gap, and participants suggested that additional partnerships could be made with existing NGOs who are active in this space, although no other organization was specifically named. The need to continue advocacy efforts related to equitable access to diagnostic services was frequently mentioned by participants.

4.2.5 Other Feedback on Structure, Scope, and Resources

The few participants who commented on changes to SCI's transition to Phase 2 provided differing views. An Education/Quality Improvement Advisory Group was formed in Phase 2 by revamping the Nursing Working Group, the Sickle Cell Working Group and other initiatives from Phase 1, such as the haematology/oncology fellowships. This was perceived by some participants as having resulted in reduced resources for nursing- and SCD-related activities, whereas others thought the move was *"a logical step based on the progression of the intervention."*

4.3 Key Evaluation Question 3: Has SCI been effectively preparing for the post-SCI phase?

When asked if SCI has been effectively preparing for the post-SCI phase, three types of responses emerged from the data shown in Figure 6 on the next page. Interestingly, even though participants varied in their sentiment about the level of readiness for transitioning to post-SCI, they mentioned a number of the same risk factors and enabling factors related to this transition.

4.3.1 Risk Factors/Challenges

Government Engagement & Inter-governmental Collaboration

Although mid-term evaluation had reported that "*there is good buy-in from local governments,*" (p.31) some countries reported challenges with government engagement, which one Caribbean physician defined as "*actually investing money into diagnosis and care of children with cancer and blood disorders.*" There were concerns that if governments don't make a commitment to this field it could "*derogate the gains*" made so far. When they were asked to elaborate on the factors that make government engagement challenging, participants cited the small number of paediatric oncology cases compared to other diseases, and the

perceived cost, misinformation, and social stigma associated with sickle cell disease.

Additionally, while a vision where all children in the region can benefit from haematology/oncology services was deemed ideal, participants were concerned that when emergencies such as the recent COVID-19 pandemic happen, each government "*will be focused on their own medical system, based on the capacity they have,*" and it would prove difficult to unify efforts.

"My burning issue is government engagement. Childhood cancer is not a priority here, cost is high, the number of cases is small. We have tried and tried but it hasn't worked. It hurts, a child with cancer, it's devastating for the parents and for society. Same for sickle cell disease." —Caribbean physician

"There are many passionate local leaders, but this is not enough if they do not have the government support to mobilize and sustain change." —Project management team member

"What I was hoping to see is more dialogue with my local government. Now that we are in transition, I haven't seen recent dialogue. It's important to have this dialogue with the local governments to help us for post-SCI. I think SCI could do more." —Caribbean physician

The Emotional Burden of SCI 'Ending'

Some participants said the thought of SCI 'ending' was too emotionally difficult and might explain why some stakeholders were "*low in energy*" when it comes to engaging with post-SCI strategy planning. Losing case consultation activities was the most frequently discussed fear. At the same time, there was a broader sentiment that the Caribbean partners should own the strategy and effectively prepare for post-SCI.
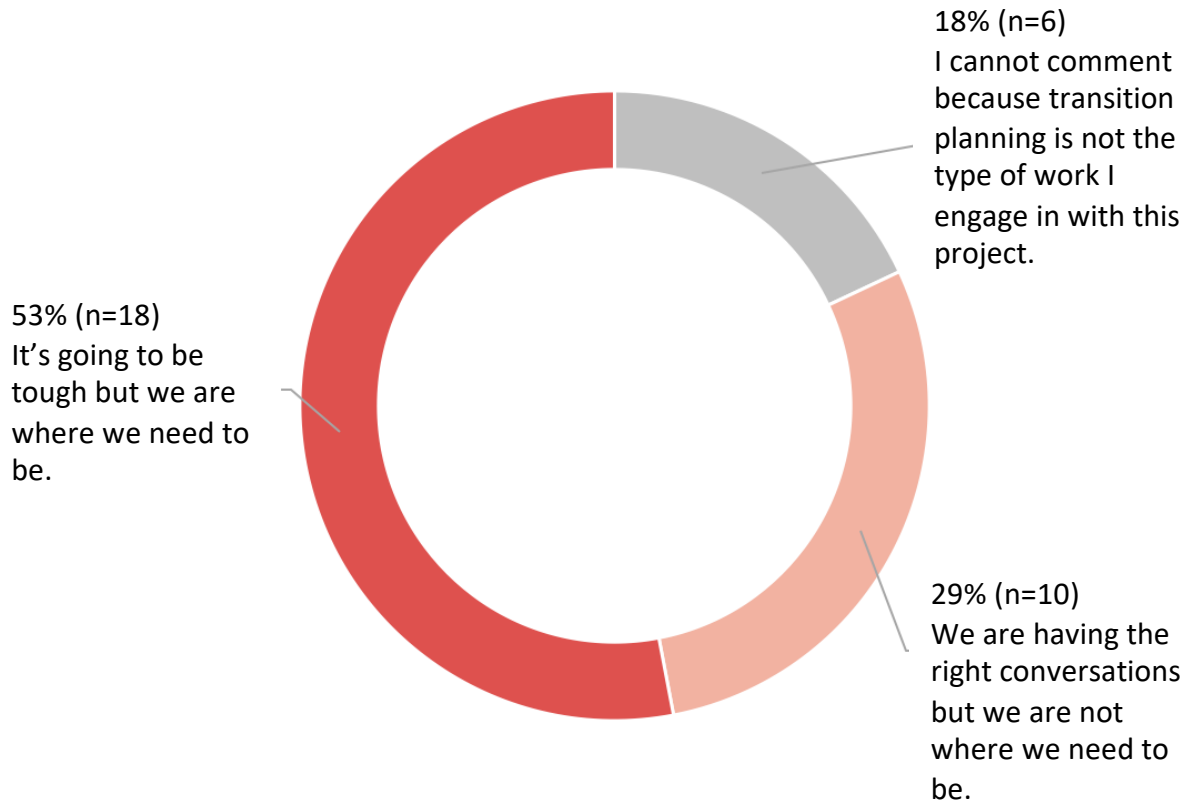
"I say we are not ready, but I don't think it's necessarily all on SCI. We, the Caribbean partners, should have been preparing earlier for post-SCI [pause, sigh], it's difficult." —Caribbean physician

"We have enjoyed the governance and resources that SCI has brought, but for individual countries, it [the post-SCI phase] is going to be difficult. Even though we know SCI will end, we want it to stay, so I think that's one of the reasons the energy is not there to develop the post-SCI. But the onus is on the Caribbean partners, the exit strategy is for us to develop." —Caribbean physician

Difficulty Articulating the Post-SCI Strategy

The post-SCI strategy seemed "*unclear*" and "*difficult to conceptualize*" to a few participants. They were unsure of what the transition means in terms of "*concrete steps*" and "*the actual how.*" They

Figure 6: Three types of responses emerged when the participants were asked whether they think SCI has been effectively preparing for the post-SCI phase.

18% (n=6)
I cannot comment because transition planning is not the type of work I engage in with this project.

53% (n=18)
It's going to be tough but we are where we need to be.

29% (n=10)
We are having the right conversations but we are not where we need to be.

wondered if more could be accomplished between annual general meetings to discuss and clarify the priorities and structures for post-SCI. At the same time, they acknowledged how difficult it has been to bring the group together due to heavy workloads and varying schedules across six countries.

> *"We need to discuss post-SCI strategy more because it's not clear yet. […] I know everyone is busy but we have Zoom now. Maybe we could meet in smaller numbers and then all come together once a year in the general meeting."* —Caribbean physician

Project Management Duties

Several participants were unclear as to how key program activities would continue post-SCI if the project management support, currently offered by SickKids, were to end. This issue was also uncovered in the mid-term evaluation (p.30). One person wondered if the staffing model implemented for data managers could be duplicated for post-SCI project management, enabling each site to have a project manager.

4.3.2 Enabling Factors

Strong Foundation

Participants said the foundation on which post-SCI can build on is strong:

- A high-trust, international community of practice has been created (see Section 4.1.3). According to one Caribbean physician, *"SCI brought physical leads closer together… this can't be understated. Trust is crucial for sustainable partnerships in the post-SCI phase[…] frank discussions, can only happen when there is trust."*

- A pan-Caribbean commitment exists between partners. The participants said that it became clear during the 2019 Annual General Meeting that SCI partners had a desire to continue working t*ogether* instead of individually.

- Necessary technology infrastructure for paediatric haematology/oncology has been established through telemedicine facilities and increased use of Zoom, making it possible to work and share knowledge across the region, even when emergencies such as COVID-19 restrict mobility.

- Investment in health human resources by nature has a domino effect as the physicians and nurses trained through SCI become the trainers and mentors for others, as indicated by results shown in Section 4.1.4, paving the way for further achievements in the post-SCI phase.

- A group of SCI leaders (at SickKids and locally) that have *"a lot of good energy pushing us forward"*, have *"gone out of their way to make this happen"* and were described as devoted and passionate.

> **Caribbean physician:** *We started [the last annual general meeting] with a shocking fundamental question: Do you actually want to continue with this collaboration? I was surprised by a strong yes!*
>
> **Interviewer:** *Why were you surprised they all said yes?*
>
> **Caribbean physician:** *Historically in the Caribbean setting people got what they got for their own islands. For example, I could say, oh well, my island is already doing great and has achieved a lot, we don't need the burden of being part of this collaboration. It was enlightening to see their commitment to the region, not just their own island.*

Transition Advisory Committee

Participants said that the group has assigned a group of SCI leaders to be part of a Transition Advisory Committee. The existence of such a committee was itself taken as *"a sign of awareness and commitment to a successful post-SCI,"* according to one Caribbean physician.

Interest from the Business Community

A meeting in Orlando, Florida, in December 2019 brought together SCI partners with individual and corporate donors who had supported SCI since its inception. The meeting was attended by individuals in key roles, including presidents and CEOs of banks and insurance companies (SCI Advisory Committee Meeting in Florida, 2019, Meeting Minutes) and was described as "*very successful*" by two participants who were in attendance. The attendees of this meeting have formed an advisory group, which is an indicator of their level of interest in supporting the post-SCI phase.

4.3.3 Priority Transition Activities

The following activities were reported as being the most important priorities for post-SCI planning:

Governance

The formation of a governance structure was the most spoken-about transition activity related to this topic. One Caribbean physician said: "*without governance, we can't go long.*" Another stated, "*good governance leads to credibility, which is a prerequisite to donor engagement.*" There was a belief that donors trusted SickKids because of its track record, and whatever form the post-SCI governance model takes, it should include a respected entity, such as

the University of the West Indies (UWI), that has its own "*track record of dedication to the region.*" One Caribbean physician described the UWI as "*the best link that connects us all together.*" The university's status as a Canadian Revenue Agency qualified donee and its experience administering large grants were mentioned as other factors for consideration.

Government Engagement

Government engagement was thought of as a priority area for transition planning. Since CARICOM is a platform for individual Caribbean governments to come together, it was mentioned as a possible venue to increase government engagement. Continuing to work with the Pan American Health Organization (PAHO) was mentioned as another important pathway to engage governments.

"*During CARICOM, heads of governments come together. So if we talk to our MoH, explain the benefits with proper framing, CARICOM would be a good venue. It could be beneficial to them (policy makers) too! They can say they did something good for the region.*" —Caribbean physician

"*Instead of me with my one small voice, PAHO is able to do a full [health] system analysis and get governmental backing. Therefore for post-SCI this is an important activity to look at.*" —Caribbean physician

Finance

In terms of a financing model, one participant recommended that the post-SCI phase should try to find a core investor, because it provides a degree of stability for the project, especially in times of emergencies, and then find additional ad-hoc funding.

Public-private partnerships were described as necessary and two examples were mentioned. Firstly, the RBC/RBTT Caribbean Children's Cancer Fund, which provides support for children's cancer care in The Bahamas, Barbados, Trinidad and Tobago, and St. Lucia. Secondly, the support provided by the American Society of Hematology (ASH) for the C-ICAL initiative (Section 2.2.2). ASH will support data managers in The Bahamas, Barbados, Jamaica, and Trinidad & Tobago until at least 2022 so that leukemia data will continue to be gathered and analyzed.

Ongoing M&E

Participants said that at this point in time when a transition is taking place, there is a need for ongoing evaluation to provide the

partners with real-time feedback as they navigate the changes.

"Someone has to say you are dropping the ball here or you are doing this well. At the beginning [of post-SCI], we need evaluation more frequently, then we can do it less often." —Caribbean physician

"After all that has been achieved, it will be a shame to fail by not understanding how we are doing. Ongoing evaluation is important because there is a lot of structure that we should put into place for Post-SCI to help with how we are moving forward.." —Caribbean physician

Integrating Emergency Planning into Post-SCI Planning

The participants said that COVID-19 has highlighted "*the need to be proactive*" and the importance of integrating emergency planning into post-SCI planning. One recommendation by a Caribbean physician was using the lessons learned during COVID to develop a guideline "*to assist us to determine what we have to do when these emergencies arise.*"

"People don't think of COVID as an opportunity, but it is, we should take advantage of it to put things in motion for care not to fail when these issues arise again." —Caribbean physician

4.3.4 Vision for Post-SCI

Although the interview and survey questions did not explicitly ask about the participants' vision for post-SCI, the subject emerged organically. Some perspectives are shared in the quotes below.

"The momentum is there and I hope when SCI in this form is over, that the energy remains, so we can train surgeons and pharmacists, so we can holistically treat our children in the region. My dream is to be able to do transplants some day." — Caribbean physician

"To be able to treat the children holistically, by inter-professional teams of nurses, pharmacist, pathologists, surgeons, radiation therapies with paediatric expertise, paediatric radiologist, etc." — SickKids physician

"Rather than seeing it 'end,' I would like to see it continuously evolve toward greater Caribbean autonomy, with continued engagement from SickKids at whatever level best supports continued diagnostic and treatment improvement for children with cancer and blood disorders." —Project management team member

5. Conclusions

This evaluation used OECD's evaluation criteria (2019) to determine the relevance, effectiveness, efficiency, coherence and sustainability of SickKids-Caribbean Initiative, using the three key evaluation questions discussed in section 4.

5.1 Relevance

Based on the findings, the evaluation found SCI to be highly relevant to the needs of the SCI partner countries as a whole and to the needs of individual members. SCI helps to fill a large gap in the diagnosis, treatment, and care for children with cancer and blood disorders in the Caribbean. In the words of a member of the SCI project management team, from the start, SCI strategy has *"emphasized local autonomy/ accountability, balanced with an appreciation of resource limitations in the Caribbean."* Activities have been designed with the aims of making them relevant to the local context and increasing the likelihood that they will be sustainable. For example, localized and context-specific clinical care guidance documents were perceived as useful and culturally relevant. Similarly, during case consultations, treatments options took into consideration resources available to local specialists.

5.2 Effectiveness

The findings in Section 4 validated SCI's logic model, showing that it has achieved its desired outcomes. The pathways described in Section 4 add detail and nuance to the SCI logic model. The three most significant outcomes may have slightly different labels —because the consultant wanted to stay true to the participant's descriptions – but they are conceptually the same as the intermediate outcomes listed on the logic model, namely:

- Increased equitable access to specialized paediatric haematology/oncology care across the region;
- Improved clinical expertise to diagnose and manage paediatric haematology/ oncology patients; and
- Increased regional capacity to provide paediatric haematology/oncology care through a community of practice.

Individually and in combination, these outcomes lead to the ultimate goal of SCI: improved outcomes and quality of life for children with cancer and blood disorders in the Caribbean. The results of this evaluation show evidence that SCI delivers its intended activities and effectively achieves its outcomes.

5. Conclusions

5.3 Efficiency

Overall, the project is meeting its deadlines and the delays that were pointed out in this report were largely caused by external factors, for example, local challenges with stocks of staining reagents necessary for flow cytometry tests, or the COVID-19 pandemic that has delayed the graduation of the third cohort of nurses. Response time from both project management and SickKids physicians was commented on as being "*timely*," "*quick*," and even "*super-efficient*." Another measure of efficiency used by other capacity building initiatives has been the successful transition from one phase to another (Käser *et al*, 2016). In the case of SCI, the results show that after the transition from Phase 1 to Phase 2, the initiative continues to deliver its intended outcomes.

Results also revealed, however, that the positive outcomes associated with nursing graduates would have been even greater if not for local system-level barriers such as limits to the scope of practice or being assigned administrative duties instead of bedside care, which could be seen as an inefficient use of highly skilled human resources. The evaluation concludes that for factors in the control of SCI, the project has been efficient, but that further dialogue and advocacy around the issues highlighted here will be beneficial.

5.4 Coherence

Results have shown that SCI objectives and activities link together via complex pathways, but all support the overall goal. This evaluator did not find any evidence that any identified focus area or activity does not fit with the overall goal of SCI. Internal coherence based on data is therefore high. Several external partnerships were uncovered by this evaluation – for example, the Pan-American Health Organization (PAHO) and the American Society for Hematology (ASH) – and signaled good external coherence because they had resulted in positive outcomes and were perceived to have the potential to be beneficial to SCI and the future post-SCI phase. However, there may be other partnerships that this evaluation has not uncovered, because the scope did not include a comprehensive partnership evaluation.

5.5 Sustainability

SCI has made good progress building strong partnerships built on trust within SCI partner countries and strategic external partnerships (e.g. PAHO, ASH). Results also showed evidence of regional collaboration, local ownership, and transparent communication between SCI members. Finding the time to meet in between annual meetings was identified as a challenge due to heavy workloads and schedules across seven countries (including SickKids) but may be necessary during this transition phase. SCI has adapted its design and delivery in response to emergent information (Wiltsey et al, 2019), for example, the creation of a special group in response to data in identifying a high-risk subgroup of patients, as discussed in section 4.1.2. The fact that 96% (26 out of 27) of graduates have so far remained in the region is also a positive sustainability indicator.

Taken together, it is concluded that there are positive indicators for SCI's sustainability, but government engagement strategies need to be monitored. It also remains to be seen what kind of governance and financial models will be developed for the post-SCI phase.

5.6 Evaluation Limitations and Strengths

Of the invited participants, four did not participate, and therefore, the findings do not reflect their insights. Review of financial records was not part of this evaluation and, as such, this consultant cannot comment on this aspect of efficiency. The strengths of this evaluation include using multiple designs (interviews, survey, document review) and multiple perspectives, and incorporating both qualitative and quantitative data in the analysis.

"

Interviewer: *Is there anything else you would like to add?*
Caribbean physician: *If I could say, 'I wish SCI stayed forever,' and you would say, 'It will!'*
Pause (smile)
Interviewer: Pause (smile)
Caribbean physician: *SCI has been some of the best moments of my professional life. We know SCI in this form will end. But the friendships will stay forever.*

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Appendices

1. Demographic and Financial Characteristics of SCI Partner Countries

2. Interview Guide

3. Survey Instrument and Modification to Data Collection Strategy

4. Key Factors that Influence the Transition of Global Health Program

5. SCI in the Words of the Participants

6. Facility Based Training/Quality Improvement Initiatives

Paediatric population size and health finance mechanisms in each of the six SCI partner countries.
'Out of pocket spending' are payments by individuals for health services. 'Government health spending' is domestically financed government expenditures on health. 'Prepaid private spending' includes private insurance and non-governmental organizations' spending on health. 'Development assistance' includes financial and in-kind contributions from global health channels. Three countries (The Bahamas, Barbados, and Trinidad and Tobago) are considered high income and do not qualify for international aid/grants, despite being low-resourced.

	The Bahamas	Barbados	Jamaica	St Lucia	St Vincent & the Grenadines	Trinidad & Tobago
Total population (000)	385[2]	286[2]	2948[3]	183[3]	111[3]	1389[2]
Total under-18 population (000)[2]	106	61	845	42	30	337
Gross Domestic Product, per capita (2018)[1]	32218	17949	5354	10566	7361	17130
Total expenditure on health, per capita[4]	1938	1188	314	511	277	1048
Out of pocket spending, per capita[4]	537	544	66	245	52	426
Government health spending, per capita[4]	966	557	188	200	189	546
Prepaid private spending, per capita[4]	434	87	54	31	7	76
Development assistance for health, per capita[4]	0	0	5	36	29	0

Sources:
1. World Bank National Accounts Data (2018); 2. UNICEF Data Warehouse (2018);3. Countdown 2030 Country Profiles (2019); 4. Financing Global Health Database (2018)

Appendix 2: Interview Guide

Interview #:

Date of interview:

Context:

SCRIPT: *Welcome and thank you very much for your participation today. My name is Roxana Salehi from Vitus Consulting and I was hired by SickKids CGCH to evaluate the SickKids-Caribbean Initiative. An information sheet about the purpose of this evaluation was sent to you at the time of scheduling, which said that we are doing this evaluation to better understand if SCI is meeting its intended results, to document key learnings, and to better understand what's needed for a successful post-SCI phase. This interview will take about 45 minutes to one hour and will include five questions. Your participation is completely voluntary and you will not be identified if quoted in any documents resulting from this study, but please note that due to the small number of people we are talking to, we cannot guarantee anonymity. At this time, I would like to ask you for your consent to participate in this study. I also would like your permission to record this interview, so I may accurately document the information you convey. Once I complete my notes, I will delete the audio/video file.*

Do you have any questions before we begin?

Q1. From your point of view, what have been two or three of the most important outcomes of SCI to date?

Q2 Within its current structure, scope, and resources, are SCI activities meeting the needs they have been designed to meet in the region?

Probe: Are there ways they could better meet those needs? (i.e. how could they become more relevant, more efficient, more effective, etc.)

Q3. Has SCI been effectively preparing for the post-SCI phase? Please elaborate.

Probe: Some of the key factors that influence the transition of global health programs

- Partnerships
- Regional collaboration
- Finance (economic viability, stability, efficiency)
- Local ownership
- Governance/leadership
- Clear strategy (long term goal, logic model)
- Adaptability Program monitoring and evaluation
- Strategic communication
- Global macroeconomic trends

Q4. In the last few years, have you noted any unanticipated outcomes of SCI? Unanticipated outcomes are those that you didn't necessarily plan for but they happened organically and they could be positive or negative.

Q5) Is there any important question that I didn't ask? Is there anything else about SCI that you would like to share with me?

Thank you and have a great rest of the day!

Appendix 3: Survey Instrument and Modification to Data Collection Strategy

Originally, survey participants were meant to attend two focus groups, but due to the COVID-19 pandemic a qualitative survey was chosen as a better alternative to focus groups that would have proven very challenging for individuals to attend.

Page 1. Survey Introduction

Dear Participants:

Before you begin, please take a moment to review the following:

This survey is set up as **anonymous.** We don't ask for your name and do not collect any personal information about you except for your role within SCI. If we quote your responses in the report, it would say for example: "*Survey Participant- Caribbean Physician"*. However, due to the small number of participants, we cannot guarantee full anonymity.

This survey has five questions, the first three require longer answers (maximum of 300 words, approximately half a page single-spaced) and the last two require shorter answers (a few sentences).

You can **save** your work and return to it later to complete it:

Press 'SAVE' at the bottom right corner of the page. Either save the link that the software gives you, or, simply provide your email address so that the survey software can email you a link to your saved responses (the email address that you provide is not shared with the consultant). *Please ensure you save your link/email and check your 'Spam Folder' in case the email ends up there.

Survey **will close on Monday June 15** at 10 PM Eastern Standard Time.

Thank you for providing your candid feedback!

Page 2. Demographic Information

Which of the following best describe your role within SCI? :

❑ SickKids nurse

❑ SickKids physician

❑ Project Management Team

❑ Caribbean nurse

❑ Caribbean physician

Page 3. Survey Questions

1. From your point of view, what have been two or three of the most important outcomes of SCI to date? Please give specific examples.

2. Within its current structure, scope, and resources, are SCI activities meeting the needs they have been designed to meet in the region? Are there ways they could better meet those needs? *If it helps, refer to the table below. It's a list of SCI activities. Feel free to comment on whichever ones that are most relevant to you*.

3. Has SCI been effectively preparing for the post-SCI phase? Please elaborate. *If it helps, take a look at the list below, but you can also discuss anything that **you** think is important, it doesn't have to be on this list.*

4. In the last few years, have you noted any unanticipated outcomes of SCI? Unanticipated outcomes are those that you didn't necessarily plan for but they happened organically and they could be positive or negative. (Short answer, a few sentences)

5. Do you have any other comments about SCI that you would like to share with the evaluator? (Short answer, a few sentences)

Thank you for your participation!

Appendix 3: Survey Instrument and Modification to Data Collection Strategy

Visual aid for question 2:

Visual aid for question 3:

Education

- Telemedicine education sessions
- Paediatric Haematology/oncology physician fellowships – and other - training at SickKids
- Paediatric Haematology Oncology Nursing Education Program
- Facility-based training and Quality Improvement
- Funded/facilitated participation in specialist professional society (American Society for Pediatric Hematology/Oncology) meetings, conferences, and courses
- Patient and family education materials

Case Consultations

- Case consultations (including ad hoc and regular leukemia and lymphoma rounds for Jamaica)
- Diagnostic testing
- Clinical and supportive care guidance documents

Local Oncology Databases

- Collection of oncology data
- Collective review and discussion of aggregate data
- Action planning based on aggregate data

Research, Policy and Advocacy

- Research, knowledge translation, and evaluation
- Drug availability and access study
- Support for advocacy activities

Key Factors that Influence the Transition of Global Health Programs

- Partnerships
- Regional collaboration
- Local ownership
- Strategic communication (with stakeholders and the broader public)
- Adaptability (altering program design/delivery to ensure effectiveness)
- Program monitoring and evaluation
- Finance (economic viability, stability, efficiency)
- Governance
- Leadership
- Clear strategy with a long-term goal
- Global macroeconomic trends (e.g. Pandemic, climate change)

Appendix 4: Key Factors that Influence the Transition of Global Health Programs

- Partnerships
- Regional collaboration
- Local ownership
- Strategic communication (with stakeholders and the broader public)
- Adaptability (altering program design/delivery to ensure effectiveness)
- Program monitoring and evaluation
- Finance (economic viability, stability, efficiency)
- Governance
- Leadership
- Clear strategy with a long-term goal
- Global macroeconomic trends (e.g. pandemic, climate change)

Sources: Iwelunmo, *et al.*, 2016; University of Washington Program Sustainability Assessment Tool, 2012; Bao, 2015.

Appendix 5: SCI in the Words of the Participants

"Though SickKids doctors are formally part of this project, they have become friends. They generously share their time and talent and experience." —Caribbean physician

" The heart and soul that goes into SCI is phenomenal. Dedicated Caribbean leads who are incredibly passionate." —Project management team member

"I think SCI is a wonderful program that has matured into a sophisticated network of experts/'family' providing support on many levels." —Project management team member

"What's incredible is the devotion and leadership of those involved with SCI, both at SickKids and all our Caribbean partners." —Project management team member

"SCI partners have gone out of their way to make this happen and help the region." —Caribbean physician

"Everything has been transparent, information about fund flow and other communication." —Caribbean physician

"My experience has been gratifying, open and professional relationships. We can share our perspectives without fear of SCI pulling out. SCI was clear, very early in the game, that this is a finite time engagement, so that was extremely useful." —Caribbean nurse

"More than any other project I have worked on, I see evidence of partnership, respect, sharing, camaraderie, and collegiality." —SickKids nurse

"It has been a privilege to work on this project." —SickKids physician

Appendix 6: Facility-based Education and Quality Improvement

To date, two customized education and quality improvement activities were delivered, one at Princess Margaret Hospital in The Bahamas and the other at Eric Williams Medical Sciences Complex in Trinidad and Tobago. Areas included sickle cell disease, chemotherapy safe handling and administration, and implementation of clinical change management. For those participants in The Bahamas who attended the 'SCD Clinical Care' and 'Supporting Child and Family' quality improvement sessions, 90% (29 responses were available) said they would recommend this session to a colleague, which is a strong indicator of the quality and relevance of the sessions. Participants in both The Bahamas and Trinidad quality improvement sessions were able to give concrete examples of how they will use the knowledge in their work. For example, two workshop participants said: " *I learned what language not to use when speaking to the child about their disease and dying*" and " *I learned I can use strength-based approach to mediating between parents and staff.*" (Source: SCI project records)