

MIDTERM EVALUATION

SICKKIDS-CARIBBEAN INITIATIVE

Final report

November 30, 2016

*Prepared by:
Cathexis Consulting Inc.*

Peter Rudiak-Gould

Melissa McGuire

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Overview of SCI

SCI builds sustainable local capacity to diagnose, treat, and manage childhood cancer and blood disorders in six Caribbean countries.

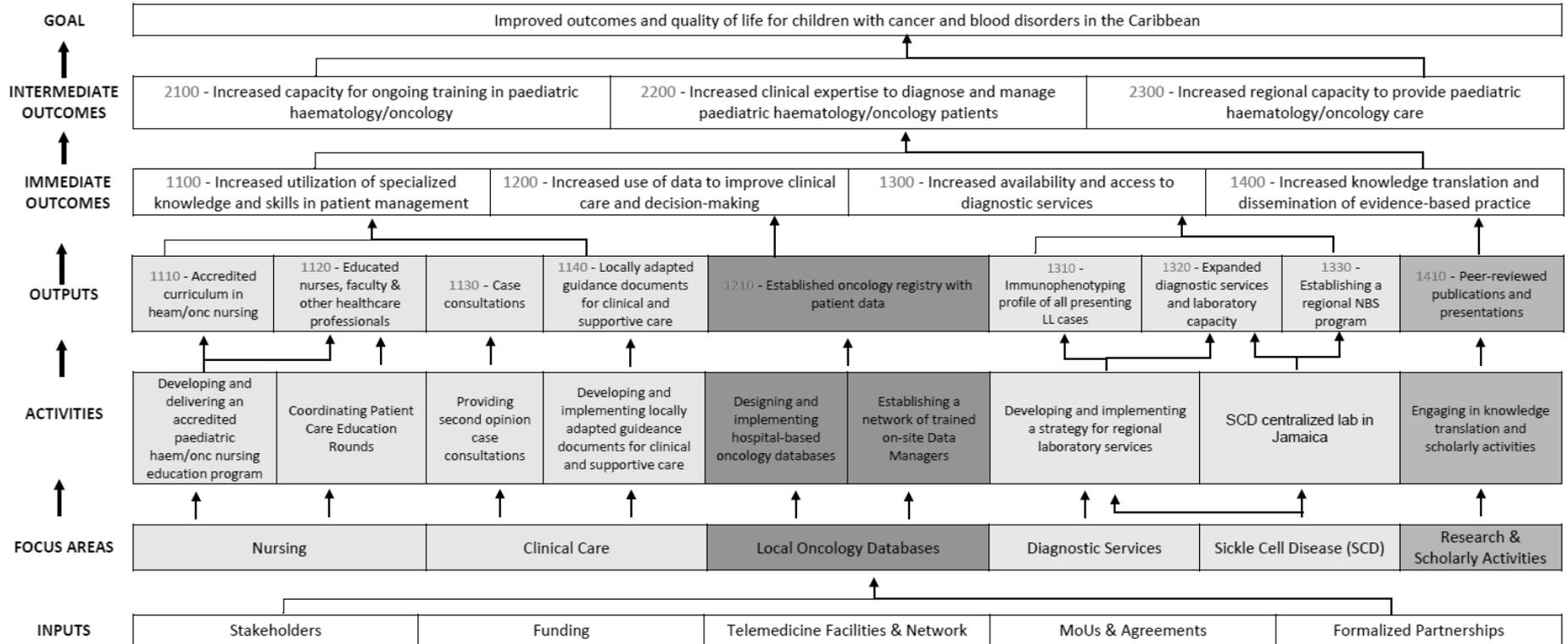
The SickKids-Caribbean Initiative (SCI) was launched in 2013 with the goal of building sustainable local capacity to diagnose, treat, and manage childhood cancer and blood disorders in six Caribbean countries (The Bahamas, Barbados, Jamaica, St. Lucia, St. Vincent and the Grenadines, and Trinidad and Tobago). Formal partnerships have been established between SickKids and key stakeholders – the University of the West Indies (UWI), Ministries of Health, hospitals and institutions – in each of the six countries.

The SickKids Foundation provided funding to SCI to be leveraged over a five-year period (2013-2018) through the Centre for Global Child Health at SickKids. SCI brings together health care specialists at SickKids in Toronto and their Caribbean counterparts at seven institutions in the six countries, and works to build capacity in six focus areas:

- **Clinical care** – through the provision of case consultation rounds, the development and deployment of clinical care and supportive care guidance documents, and the offering of fellowships and other continuing medical education opportunities
- **Diagnostic services** – including increasing access to flow cytometry facilities for diagnosing childhood leukemia and lymphoma
- **Local oncology databases** – developing, populating, and mining hospital-level databases that bring together data on cases of childhood cancer, treatments and outcomes
- **Nursing** – including the provision of nursing rounds and the launching of a pediatric haematology/oncology nursing program
- **Research, scholarly activities, and advocacy** – including support for publications, lectures, and presentations
- **Sickle Cell Disease** – including efforts to establish universal newborn screening for this disease

A detailed view of the initiative’s inputs, activities, outputs, and desired outcomes is provided on the following page through SCI’s logic model.

Overview of SCI – logic model



Purpose and methods of the midterm evaluation

Evaluation purpose

Over the course of the initiative, SCI has collected monitoring data about program activities and outputs (displayed on a dashboard – see *Appendix A*) and has produced two Annual Progress Reports (2014-15 and 2015-16).

In order to supplement this information, SickKids commissioned a midterm evaluation to collect qualitative data to explore these achievements in greater depth, identify any challenges or opportunities for improvement, and support continuous quality improvement. SickKids engaged an external consulting firm, Cathexis Consulting, Inc., to conduct the midterm evaluation.

The evaluation plan was approved by the Quality Management Group at SickKids.

* These numbers do not add up to 30 because individuals have multiple roles.

Evaluation methods

The midterm evaluation included two primary data collection methods: in-person focus groups (2 groups) with SickKids staff, and telephone/Skype interviews with Caribbean partners (n=17) and SickKids staff (n=3). (See *Appendices B, C, and D* for focus group guide, interview guide, and information sheet given to participants, respectively.)

Participants were chosen via purposeful sampling, to ensure that all 7 Caribbean institutions, 6 countries, and 6 initiative focus areas were included, as well as a variety of roles. See *Appendix D* for details of the sampling methodology. As a result, the focus groups and interviews reached 30 individuals in total (20 in the interviews and 10 in the focus groups), including:

- 7 members of the Executive Committee
- 6 members of the Steering Committee
- 7 members of the Project Management Team
- 10 Lead Physicians in the Caribbean
- 4 Lead Nurses in the Caribbean
- 10 working group leads: 2 for clinical care, 2 for diagnostic services, 1 for local oncology databases, 2 for nursing, 2 for research, scholarly activities, and advocacy, and 1 for Sickle Cell Disease
- 11 individuals with other sorts of involvement in various focus areas: 3 for clinical care, 2 for local oncology databases, 4 for nursing, and 2 for Sickle Cell Disease.
- Partners in all 6 Caribbean countries: 1 from the Bahamas, 3 from Barbados, 7 from Jamaica, 1 from St. Lucia, 1 from St. Vincent and the Grenadines, and 4 from Trinidad and Tobago.*

The findings of this midterm evaluation have drawn information from these focus groups and interviews as well as SCI's dashboard and annual progress reports. Focus groups and interviews were conducted in October 2016, so stakeholders' testimonials and perceptions are from that vantage point. The dashboard data referred to in this report is from slightly earlier: March 31, 2016 (the 4th quarter of the 2015-2016 fiscal year). Findings have been organized to align with the 6 focus areas.

Overview of findings



Clinical care

- ✓ **33** clinical consultation rounds held
- ✓ **8** guidance documents completed

” *I now can truly, with confidence, look at a child with leukemia and know that I’m offering him appropriate care.*



Diagnostic services

- ✓ Flow cytometry testing is available, through SCI, for all children in SCI partner sites
- ✓ **81** immunophenotyping tests processed

” *Every single child [at our institution] now gets a flow cytometry test before treatment.*



Local oncology databases

- ✓ Databases set up and populated at all 7 sites
- ✓ Commitment by all partners to reduce treatment-related mortality by one third

” *It was only by seeing those numbers that [reducing treatment-related mortality] arose as a goal.*



Nursing

- ✓ **13** nursing rounds held
- ✓ Pediatric Haem/Onc Nursing Program up and running in Trinidad & Tobago

” *We now have nurses who can speak with authority at the national level about children with cancer.*



Research, scholarly activities, and advocacy

- ✓ **15** lectures, **10** posters and abstracts, and **1** peer-reviewed article
- ✓ Presented in both regional and international venues

” *SCI has turned the light on to childhood cancer and haematology.*



Sickle Cell Disease

- ✓ Newborn screening now island-wide in Jamaica, with a pilot in St. Lucia
- ✓ Testing now done by HPLC/isoelectric focusing facilities in Jamaica; **25,000+** tests completed

” *I get the child in a quarter of the time that it used to take.*



Other impacts

- ✓ A South-South community of practice is being forged
- ✓ The project’s momentum has boosted regional fundraising and advocacy efforts



Sustainability

- ! When SCI ends, scarce resources and shifting government priorities may erode the project’s gains
- ➔ Consider an SCI Phase II focused on consolidating the project’s successes

Overview of findings

Successes

Overall value of the initiative

Stakeholders at SickKids and across the Caribbean spoke in **highly positive** terms about SCI. They praised both the **process** (strong partnerships and close collaboration) and the **impacts** (increased capacity and improved patient outcomes) of the initiative. The feedback from partners indicate that **capacity in each of the 6 focus areas and in all 6 countries has indeed increased**, and is **expected to continue increasing** for at least the duration of the project and likely beyond.

Notable impacts

- Local oncology databases have already revealed a priority area for improvement—namely, that treatment-related mortality in the 6 countries is excessively high—and led to a tangible **commitment by all partners to reduce treatment-related mortality by one third**. If successful, this could save many children’s lives.
- Greatly expanded access to flow cytometry for leukemia/lymphoma diagnosis allows partners to better tailor their treatment, making the goal of reducing treatment-related mortality an achievable one. Together with expanded access to newborn screening for Sickle Cell Disease, Caribbean **children are receiving diagnoses and treatment for cancer and blood disorders more quickly and systematically than before**.
- Guidance documents, rounds, fellowships, conferences, and the new pediatric haematology/oncology nursing program have **made specialist knowledge of cancer and blood disorders available to Caribbean partners** in a way that can be applied in their unique settings.
- The project has brought Caribbean partners together physically and virtually, helping to **forge a South-South community of practice** that will likely endure past the project’s end.
- SCI’s momentum and the prestige of SickKids’ involvement have **boosted advocacy efforts in the partner countries, increasing their ability to secure funding and support for the cause** from governments, foundations, and corporations going forward.

Enablers of success

Stakeholders attributed SCI’s success to the **dedication** of stakeholders, the **responsiveness** of SickKids staff to partners’ feedback, SickKids staff’s **understanding of the Caribbean context** (including its resource constraints), and the **strong partnerships and robust institutional frameworks** that were created before the project began in earnest.

“This has been a very, very positive collaboration.... It’s a wonderful model of multi-sectoral partnership.” – *Nurse*

“I now can truly, with confidence, look at a child with leukemia and know that I’m offering him appropriate care.” – *Lead Physician*

“It has inspired us to...treat [patients] like family and put ourselves in their shoes. It’s brought a family feel to everything.” – *Lead Nurse*

“SCI gave us an air of relief: ‘Someone’s taking care of that. It can actually happen.’ It has built up the positive vibes about childhood cancer.” – *Lead Physician*

“Organizations often come to the Caribbean, take pictures and don’t stay. Whereas [the staff at] SickKids actually care. They listen. They want to make sure that it’s done properly.” – *Lead Nurse*

Opportunities for improvement

Incremental improvements

SickKids could take the following actions to enhance the project's success:

- **Clinical care:**
 - Increase the number of cases covered in **case consultation rounds** by streamlining the process. Separate case consultation rounds into consultative and educational functions: hold frequent consultation rounds on urgent cases, and infrequent educational rounds on interesting cases. Provide SickKids expert consultants with a desk aid of what facilities are available in each site, and guidelines on when flying a patient to Toronto is possible.
 - Continue to create **clinical care guidance documents**. Foster change management capacity in partner institutions to encourage the use of the documents. In collaboration with partners, monitor the use of these documents and evaluate their impact.
- **Diagnostic services.** Continue work to develop flow cytometry facilities in the region. Explore the possibility of alternative testing/shipping arrangements with labs in the US.
- **Local oncology databases.** Continue discussions with partners on the possibility of sharing data between countries in a trusting, collaborative, and non-judgmental environment. Assist partners in using data for advocacy purposes. Consider how the databases may be used—or altered—for the purposes of epidemiological studies and other research projects suggested by partners.
- **Nursing.** In order to increase attendance at nursing rounds, raise awareness of the alternate methods of participation (watching video recordings and reading hard copies after the fact), and make sure all partners realize that certificates of attendance are offered. Help partners ensure the long-term viability of the nursing program: this may involve securing permanent, dedicated faculty, expanding it into a general pediatric nursing program, and advocating for legislative change so that nurses can use their newfound skills when they graduate.
- **Research, scholarly activities, and advocacy.** Continue supporting partners in publications, presentations, and other scholarly activities, but with an eye towards handing off ownership to the partners. Discuss possible scholarly uses of the REDCap data, and ways to reach out to governments and the public, not just academics.
- **Sickle Cell Disease.** Assist Jamaican partners in achieving truly universal newborn screening. Evaluate the success of St. Lucia's pilot program, then scale it up and out. Assist partners in convincing governments of the effectiveness and cost-effectiveness of newborn screening.

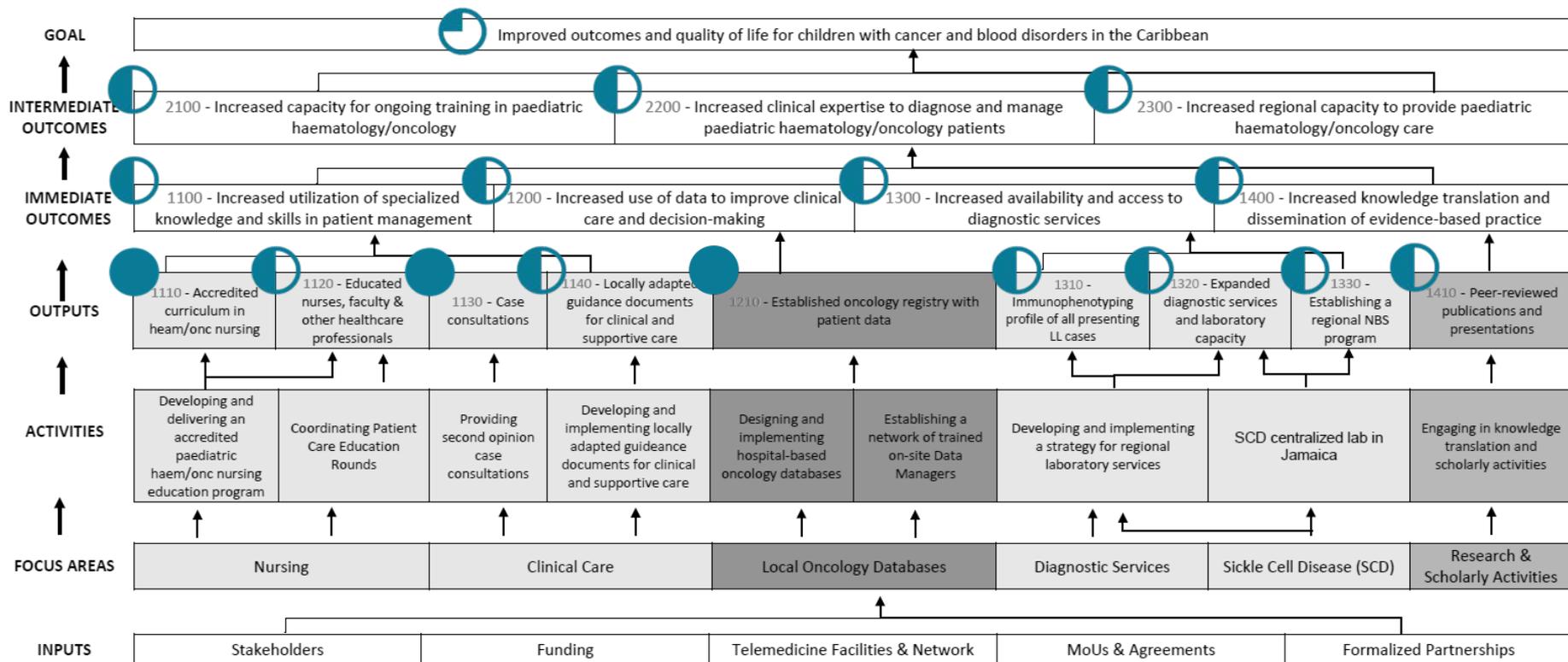
Ensuring sustainability

The only area of significant concern is sustainability. When the project ends, partners will face **scarce resources, shifting government priorities, and a lack of a project management team** to push things forward. Ensuring sustainability will require using data to show Caribbean governments that continued investment in childhood cancer and blood disorders is **needed and cost-effective**. It will require grooming **local champions** for the cause, forging **public-private partnerships**, and (possibly) connecting the pediatric cause to a wider, **all-ages** cancer and blood disorders plan. An **SCI Phase II** could help to consolidate the project's gains.

Overview of findings – progress on outputs and outcomes

The dashboard data (see *Appendix A*) shows that the project has made good progress toward achieving its intended **outputs**. Perceptual data from stakeholder interviews and focus groups indicates that these **outputs** are, in turn, successfully driving **immediate and intermediate outcomes**. There is some perceptual evidence that the project has begun to achieve its ultimate **goal**: “improved outcomes and quality of life for children with cancer and blood disorders in the Caribbean.”

The chart below summarizes the progress (as of October 2016, when focus groups and interviews were conducted) on SCI’s outputs, outcomes, and end goal. Further details are provided on the next page.



Achieved*

*May still be ongoing, but is fully in place.



In progress



Nascent

	Item	Status	Description
Outputs	1110 - Accredited curriculum in haem/onc nursing		Partners confirm that this program is accredited and is already educating its first cohort.
	1120 - Educated nurses, faculty & other healthcare professionals		Nurses are benefitting from nursing rounds. 2 pediatricians have completed SickKids fellowships and one is ongoing. Nursing program has only just begun; its greatest benefits will accrue in the future.
	1130 - Case consultations		Case consultations are fully implemented and ongoing, using newly installed telemedicine facilities at SickKids and in all 6 Caribbean partner countries.
	1140 - Locally adapted guidance documents for clinical and supportive care		8 guidance documents (5 for supportive care and 3 for clinical care) have been completed and disseminated. Creation of clinical care guidance documents is behind schedule; 20 await completion.
	1210 - Established oncology registry with patient data		In all 7 sites, data managers have been hired and trained, and databases have been created and populated.
	1310 - Immunophenotyping profile of all presenting LL (leukemia and lymphoma) cases		Testing is available free of charge for all patients at the 7 sites. However, both SickKids and UHWI have processed far fewer tests than the target.
	1320 - Expanded diagnostic services and laboratory capacity		Jamaica now has capabilities in Sickle Cell Disease screening (HPLC and isoelectric focusing) and cancer diagnosis (flow cytometry). There have been challenges developing lab capacity elsewhere.
	1330 - Establishing a regional NBS (newborn screening) program		Almost all infants in Jamaica are now screened at birth for Sickle Cell Disease. A pilot project to do the same in St. Lucia is not yet complete. Other countries have varying levels of readiness to follow suit.
	1410 - Peer-reviewed publications and presentations		The project has produced 15 invited lectures, 10 posters/abstracts, and 1 peer-reviewed publication. Stakeholders look forward to more research outputs.
Immediate outcomes	1100 - Increased utilization of specialized knowledge and skills in patient management		Partners indicate that the knowledge gained in rounds, guidance documents, etc. has begun to guide patient management practices.
	1200 - Increased use of data to improve clinical care and decision-making		A tangible goal has arisen from the data: to reduce treatment-related mortality by one third. Partners hope to use the data for advocacy and epidemiological research as well.
	1300 - Increased availability and access to diagnostic services		Flow cytometry testing is available for patients at all 7 sites, but there is still reliance on sending samples to Canada. Jamaican newborns are screened for Sickle Cell Disease, but many others are not.
	1400 - Increased knowledge translation and dissemination of evidence-based practice		Presentations, lectures, posters, and a publication have been forthcoming. Partners are participating in regional and international conferences.
Intermediate outcomes	2100 - Increased capacity for ongoing training in paediatric haematology/oncology		Nursing program is in place and expected to continue. Graduates are expected to train others and run nursing rounds when they are finished studying.
	2200 - Increased clinical expertise to diagnose and manage paediatric haematology/oncology patients		Partners report that their expertise has increased and is continuing to increase, due to rounds, guidance documents, fellowships, etc.
	2300 - Increased regional capacity to provide paediatric haematology/oncology care		Partners report that capacity in diagnostics, clinical care, supportive care, etc. has increased in each site.
Goal	Improved outcomes and quality of life for children with cancer and blood disorders in the Caribbean		Some partners indicate that SCI's benefits are beginning to trickle down to patients, but this is not yet confirmed. Databases will reveal changes in outcomes (if any) but will not speak to quality of life.

Detailed findings

organized in alignment with the 6 focus areas of SCI

Organization of detailed findings

Organization

The detailed midterm evaluation findings that follow have been organized into the following sections and subsections:

- Clinical care
 - Case consultation rounds
 - Guidance documents
 - Continuing medical education
- Diagnostic services
- Local oncology databases
- Nursing
 - Nursing rounds
 - Nursing program
- Research, scholarly activities, and advocacy
- Sickle Cell Disease
- Unintended impacts
- Implementation and project management
- Sustainability

Clinical care

Introduction

The clinical care focus area works to ensure that physicians and other members of a multidisciplinary health team follow best practices in treating pediatric cancer and blood disorders. These practices must align with international standards while being feasible within the resource limitations of each partner country.

SCI's work on clinical care has included:

- **Case consultation rounds** via newly installed telemedicine facilities. Physicians in the partner countries submit their cases for inclusion in the rounds, and receive advice on those cases from expert consultants at SickKids. (n=19/22)*
- **Guidance documents**, including clinical care guidance documents geared mainly towards physicians, as well as supportive care guidance documents aimed at a multidisciplinary team. These are written protocols, prepared by SickKids staff in collaboration with partners, for treating and managing children with particular conditions related to cancer and blood disorders. (n=20/22)*
- **Continuing medical education**, including the training of pediatric haematology/oncology fellows at SickKids, sponsored memberships in international organizations related to pediatric haematology/oncology, and other continuing medical education grants . (n=5/22)*

Spreading best practices

“There have been times when we’ve exhausted every possible way to help a patient, with no results. [SickKids] gives us advice on what they would have done. Sometimes it turns out that there is nothing more they could have done for that patient, even at SickKids. So it lets us see where we are going right, and also when we need to try something new. We depend on [the case consultation] rounds heavily...to give the patient the best chance.” – Nurse

*These numbers indicate the number of stakeholders who provided statements on this topic. For the purposes of this count, each focus group is considered one stakeholder.

Successes

Progress to date

As of March 2016, **33 rounds have been held** in which **58 cases have been discussed**. The project appears to be **on track to reach the targets** of 55 rounds and 110 cases. **Telemedicine facilities have been created in all 6 countries**, enabling these rounds.

Use of case consultation rounds

Partners use the rounds to:

- **Get advice on their own difficult cases (10)**. “In the past, you’d have to write a letter to SickKids and wait 2 to 3 weeks for a response.” – Lead Physician
- Learn about **other physicians’ cases for future reference (4)**. “Pediatric cancer is rare so you get a particular type and then not see it again for a few years. So you think ‘I remember someone had that case before.’ It’s definitely useful from that point of view.” – Lead Physician
- **Learn about interesting cases (2)**.

Positive changes in clinical practice

When asked directly whether these rounds have resulted in changes in clinical practice, partners said that they had (8). It appears that this mainly happens when **partners get advice on their own cases, which they then follow**.

Decreased isolation

Physicians in smaller countries indicated that, without the case consultation rounds, they are **alone and have no pediatric haematology/oncology colleagues to discuss cases with**. Partners felt that the rounds are strengthening ties between doctors in the Caribbean (2).

A multidisciplinary team, not just doctors, attend the rounds (4).

Access to expert knowledge

The success of the rounds owes to the **expert specialist knowledge of the consultants at SickKids (10)**. (“I think people in the Caribbean really do appreciate that you can say ‘I’ve reviewed this with a doctor at SickKids.’” – Lead Physician). A stakeholder at SickKids described the clinical consulting team as “world-class, fully staffed, no-holes, superb, complete children’s blood, cancer, and transplant specialists.”

Context-relevant recommendations

Partners appreciate that the consultants **tailor their recommendations to what is possible in the Caribbean (2)**. Partners also emphasized the critical importance of **one-to-one email consultation that occurs between rounds (4)**, though confidentiality rules make email communication challenging (1).

Opportunities for improvement

Attendance

The most commonly cited challenge was **low attendance by partners due to busy schedules (6)**.

Separating education and consultation

Another challenge is that **the rounds have two potentially competing goals: to educate generally and to provide advice on specific cases (4)**. Stakeholders suggested separating these two functions by having **frequent consultation rounds on urgent cases, and infrequent educational rounds on interesting cases (3)**.

Streamlining

Stakeholders wanted **more cases** to be presented (3), which could be achieved by **streamlining the presentation of cases** through a PowerPoint template and strict time limits (1). One SickKids stakeholder suggested that more expert consultants from SickKids would participate in rounds if they **only had to show up**, rather than needing to prepare before and follow up afterwards.

Desk aids and guidelines

A desk aid of what facilities are available in each site would ensure that consultants do not suggest locally impossible treatments, which could **demoralize partners (1)**. Consultants also need **explicit guidelines** on when it is possible to fly a patient to Toronto (1).

Successes

Progress to date

There are two types of guidance documents: 1) supportive care; and 2) clinical care. As of March 2016, **5 supportive care guidance documents** have been completed and disseminated. This has already **reached the target**. In addition, **3 clinical care guidance documents** have been completed, out of 23 planned.

Intention to use documents

All partners who were directly asked indicated that they **see the guidance documents as valuable and intend to use them as soon as possible (5)**.

Use of documents

Some partners indicate that their institutions are **using the documents already (9)**, while only a few say they are not using them yet (3). One physician reported, “I open them and use them as a checklist in my own practice.” Specific documents that were said to be used are transfusion, nausea and vomiting, febrile neutropenia, tumour lysis, brain tumour, and leukocytosis. However, partners’ statements were quite general, making it difficult to know to what extent the documents are driving practice.

A major enabler of use is that the **formality of the relationship between the Caribbean institutions and SickKids empowers partners to put the documents to use** in their institutions (2).

Impact of document use

Partners reported that the guidance documents **standardize** care (6), assure that care follows **best practices** (4), ensure **continuity of care** when there is staff turnover (2), and **save the time** it would take to research proper protocols (2).

A Lead Physician reported, “I now can truly, with confidence, look at a child with leukemia and know that I’m offering him appropriate care. Before SCI, I was just picking up knowledge here and there. Now I have a formal step-by-step guideline.”

Fit with the Caribbean context

Partners appreciate that the documents are **created collaboratively and tailored to the Caribbean context** (3). A Lead Physician stated, “We were all involved in creating the documents, adjusting them to our local situation. It’s personal, it’s owned, and it’s what we stand guided by.”

Partners have had to further tailor the documents to their specific countries and sites (4), but this was expected and does not seem to be posing any significant challenges.

Opportunities for improvement

Creating more documents

There is **much work to be done to reach the plan for 23 clinical care guidance documents** – as of March 2016, only 3 have been completed. A Lead Physician remarked that the documents take “a lot of effort and time and collaboration to get right.”

Encouraging use

It is **unclear how much the documents are actually driving clinical practice** (3). Although 9 partners stated that they are using the documents, the examples were not very concrete or specific. Implementation requires **intentional change management strategies**, which have not yet been formulated in some partner institutions (1). Local oncology databases will be useful for tracking use (1).

Measuring impact

It is **too soon to say if the documents are improving patient outcomes** (2). Local oncology databases will reveal outcomes, but attributing any changes to the documents themselves will be a challenge.

“It’s personal, it’s owned, and it’s what we stand guided by.”
– Lead Physician

Successes

SickKids Pediatric Haematology/Oncology Fellowships

Two partners have completed two-year fellowships at SickKids and returned to their home institutions as **fully trained pediatric haematologists/oncologists**.

Stakeholders spoke highly of the fellowship program, stating that it has added **clinical capacity** to the institutions that the fellows returned to (3). One Lead Physician noted that, before the fellowship program added a pediatric haematologist/oncologist to the team, her institution had **always had to rely on an adult haematologist/oncologist** when caring for children with cancer and blood disorders. When the fellow returned from Canada, her institution began to receive more referrals of children with cancer and blood disorders. This fellow has also contributed to **training others in the institution**. Another partner noted that a returning SickKids fellow has been instrumental in moving guidance documents forward in her institution.

The fellowships have also contributed to SCI's sustainability by **creating long-term advocates and champions for the cause (2)**.

Continuing medical education

The SCI has sponsored **20 annual memberships in the American Society of Pediatric Hematology/Oncology**, which puts it **on track to reach the target** of 42. Twelve individual partners received these memberships for 1-2 years each.

The SCI has also given **7 grants for continuing medical education, on track to the target** of 14. Seven individual partners received these grants and attended the American Society of Pediatric Hematology/Oncology conference or the International Society of Paediatric Oncology conference.

Although not asked about directly, those partners who spontaneously mentioned these activities spoke of them as valuable learning opportunities (3).

Opportunities for improvement

Stakeholders gave no suggestions for improving any of the medical education activities.

Diagnostic services

Ensuring timely and accurate diagnosis

Introduction

The **diagnostic services** focus area works to enhance access to timely, accurate diagnosis of cancer and blood disorders. Timely diagnosis ensures that treatment can begin as soon as possible, improving outcomes for children. Accurate diagnosis allows physicians to target their treatments to precisely the type and severity of disease that the child has.

More specifically, the diagnostic services working group has focused on:

- **Flow cytometry**, a type of immunophenotyping used to diagnose leukemia and lymphoma, the most common pediatric cancers. Flow cytometry results can be used to stratify patients according to how much chemotherapy they require, reducing over- and undermedication and the worsened outcomes that can result. SCI has worked to build flow cytometry capacity within the Caribbean region, and to establish protocols for sending samples from Caribbean countries to be processed in a lab in Toronto. (n=16/22)*
- **Other diagnostic services for cancer** (e.g. cytogenetics, immunohistochemistry, and solid tumour identification) and **for blood disorders** (e.g. coagulation). (n=5/22)*

Another diagnostic service, newborn screening for Sickle Cell Disease, is overseen by the Sickle Cell Disease working group and is included in that section of this report.

“Without [the immunophenotyping] test, you’re shooting in the dark.” – *Lead Physician*

*These numbers indicate the number of stakeholders who provided statements on this topic. For the purposes of this count, each focus group is considered one stakeholder.

Successes

Progress to date

The University Hospital of the West Indies (UHWI) in Jamaica provides flow cytometry testing, through SCI, for all children in SCI partner sites. As of March 2016, it has **processed 22 immunophenotyping tests** from Jamaica, and is aiming at a target of 240. For the other 5 countries, SickKids has made special arrangements with FedEx to have **immunophenotyping samples delivered to Toronto** for processing; **59 tests have been processed** in this way, out of a target of 240.

Eight individuals from Jamaica, Barbados, and Trinidad have **received training in flow cytometry**.

In addition to flow cytometry, some progress has been made on **other cancer diagnostics (2)**, including cytogenetics, immunohistochemistry, and solid tumour identification. **Two** individuals from Jamaica have received **training in cytogenetics**, and **11** individuals from Jamaica, the Bahamas, Barbados, and Trinidad have received **training in coagulation**, a diagnostic technique for blood disorders.

Partners are **aspiring to increase access** to microbiology (1), minimal residual disease tests (1), and molecular testing (1). One partner wanted SickKids to provide **stains** to assist in identification of solid tumours.

Reduced treatment-related mortality

Due to increased flow cytometry capacity, treatment can now be **stratified (3)**, meaning that the amount of chemotherapy is tailored to the severity of the child's cancer. "The most important [impact of increase flow cytometry capacity] would be a decrease in early deaths [from giving too much chemotherapy].... We used to have to give every patient the full dose of chemotherapy to be sure." – Lead Physician

Reduced delays in treatment

Flow cytometry has made it **faster to receive results (3)**. "It used to take a really long time to get our results back from the laboratory. Now...if we send it on Tuesday, the result is back on Friday." – Nurse. This allows treatment to **start sooner (3)**. "If the result shows it's critical, we can start chemo immediately. Waiting puts the child at greater risk." – Nurse

Decreased barriers to access

Access to flow cytometry is now universal (8). "Every single child [at our institution] now gets a flow cytometry test before treatment." – Physician. In addition, the service is available **free of charge (5)**. "[Immunophenotyping] existed before, but it cost 400 Canadian dollars. The typical parent would have to throw a BBQ or raise funds in order to afford it." – Physician

Opportunities for improvement

Continuing to build capacity

Testing at both UHWI and SickKids is **far from reaching the target of 240 each**.

Additional flow cytometry facilities are planned for Trinidad and for the National Public Health Laboratory in Jamaica, but these have encountered **delays (2)**.

Accreditation

Accreditation of the labs that house the testing facilities is a major stumbling block (1). As a result, the partner countries (other than Jamaica) still rely on flow cytometry facilities **outside of the region (3)**. This is a concern if the goal is regional self-sufficiency. (Not all stakeholders felt that self-sufficiency was the highest priority: one stakeholder said that speedy and reliable testing from the US or Canada is better than less-speedy or less-reliable testing from a Caribbean facility.)

Shipping challenges

Sending and receiving samples is not always as fast as it could be (2). SickKids **cannot receive samples on weekends** because the office is closed and the samples have a limited window of viability (1). Shipping to Jamaica is difficult for countries that are **not connected to that country by direct flights (1)**. Partners suggested establishing an alternate **testing arrangement with facilities in Miami** in order to decrease delays (2), though this could pose challenges for management and coordination. 19

Local oncology databases

Introduction

Local oncology databases refer to **hospital-based cancer databases** at each of the 7 sites in the 6 countries. These databases use REDCap: a free, open-source platform for data capture. Each database houses cancer data from a single institution, and is owned and managed by that institution. Strict privacy and security protocols are in place, including a pre-existing understanding that these databases belong to the institutions and are not freely shared between partner countries.

Each database is supported by a data manager trained through SCI. Databases capture basic information on patient demographics, diagnoses, treatments, and outcomes, and include retrospective data going back 5 years, as well as ongoing input of prospective data. The databases include cancer patients, but not patients suffering from blood disorders. (n=22/22)*

Collecting and stewarding
information

“Databases are the backbone of the whole SCI.” – *Nurse and data manager*

*These numbers indicate the number of stakeholders who provided statements on this topic. For the purposes of this count, each focus group is considered one stakeholder.

Successes

Progress to date

At each of the 7 sites, stakeholders have:

- Set up a **REDCap database**
- Hired and trained a **data manager**
- Entered **5-year retrospective data**
- Begun to enter **prospective data**

In total, as of March 2016, **392 cases** have been entered into the database.

Stakeholders **have confidence in the integrity** of the data, due to a robust quality assurance process (2). No stakeholder expressed any serious concerns about accuracy.

Reducing treatment-related mortality

The databases have already had an impressive result. They revealed that **treatment-related mortality is excessively high**, and led to a **commitment among all the partners to lower it** by a third (7). “It was only by seeing those numbers that this arose as a goal.” – SickKids stakeholder

Usefulness of the data

Most stakeholders said that they are **already obtaining some value from the data (15)**. Stakeholders appreciated that the databases provide **outcome data (4)**, **prevalence data (3)**, and a **baseline** for comparison (3). Two partners said they have also used the data in **presentations**.

Opportunities for improvement

Possible future uses of the data

Some stakeholders feel that **the greatest gains from the data are yet to come (5)**. In the future, stakeholders plan to use the data for **information and planning (17)**, **research and hypothesis-testing (12)**, **quality improvement (10)**, **advocacy and fundraising (5)**, and **institutional reporting requirements (2)**.

More specific suggestions include using the data to:

- Correlate disease incidence/prevalence with geographical location in order to discover **environmental causes of cancer (5)**.
- **Evaluate** the overall impact of SCI (4).
- Understand the reasons for **abandonment of treatment (3)** and **treatment-related mortality (2)** (including the specific infections that children contract [1])
- Determine if **drug availability (2)**, **generic drugs (1)**, and **late referrals (1)** are worsening outcomes.
- Convince **governments and foundations** to invest in more modern **equipment (1)**, **social support** for sick children and families (1), **medication (1)**, and **medical training (1)**.

Comparing data between countries

The most commonly cited challenge is that **country-to-country comparisons are currently impossible**, due to **political sensitivities (4)**. Each country has full ownership of its data and is **reluctant to share data with other countries**, even in aggregate form, because patient **outcomes may vary significantly** from country to country (1). Since some of the countries have just one pediatric haematologist/oncologist, this ends up “**point[ing] fingers at individuals**” (1).

One SickKids stakeholder referred to the sharing of data between countries as “the highest risk, most contentious aspect of the program.” Overcoming this barrier will require creating a **trusting and collaborative environment** in which partners can learn from each other’s data and share their own without fearing blame and judgment.

Widening and deepening the databases

Other suggestions for improving the database include adding **more in-depth information (4)** (such as social aspects [1] and post-treatment outcomes other than mortality [1]), expanding the database to **haematology (1)**, creating databases in **other Caribbean countries (1)**, and ensuring that the database meets the **International Agency for Research on Cancer’s standards (1)**.

Nursing

Introduction

The nursing focus area strives to increase the capacity of supportive care staff to effectively care for children with a variety of cancer and blood disorders. This is done through:

- **Nursing rounds** (aka “patient care education rounds”) run bimonthly by SickKids experts. These are interactive sessions delivered through telemedicine facilities. Each session has a topic, with an emphasis on patient- and family-centred care. (n=20/22)*
- **The Pediatric Haematology/Oncology Nursing Program** at the University of the West Indies School of Nursing’s St. Augustine campus in Trinidad and Tobago. This recently started program offers specialized training in caring for children with cancer and blood disorders, as well as general pediatrics and leadership. Students come from all 6 SCI countries. (n=11/22)*

Improving supportive care

“It’s not all about the doctors. You need excellent support staff as well.” –
Lead Physician

*These numbers indicate the number of stakeholders who provided statements on this topic. For the purposes of this count, each focus group is considered one stakeholder.

Successes

Progress to date

As of March 2016, **13 nursing rounds** have been held (**on track to reach the target** of 24), with a total **attendance of 399**. These rounds are held in **telemedicine facilities** which SCI set up in each of the 6 partner countries. Partners appreciate these facilities (2). A Lead Nurse said, “It’s great that we can see the people we’re talking to.....It’s just like a classroom.”

Participants are generally satisfied with the rounds. The **average participant satisfaction rating is 4.37/5**, which is nearly at the target (4.45), and positive feedback was widespread in interviews (12).

Building capacity

Stakeholders felt that the nursing rounds are **effective in building nurses’ capacity** (9). One nurse said that, before these rounds, “we were just learning how to care for these children by the way, getting bits and pieces from the doctors.”

Building relationships

The rounds help to **build relationships among nurses across the partner countries (3)**. Stakeholders appreciated that the attendees are **multidisciplinary**, including not only nurses but also nutritionists, pharmacists, and physicians (5). A SickKids stakeholder explained, “Care of children with blood disorders and cancer is a multidisciplinary team-based activity....These rounds are a way to reach out to all those specialties. There’s no other way.”

Choice of topics

Two partners said that the topics of the rounds are **well chosen** because they are based on partners’ requests and feedback. Sessions that were singled out for praise included:

- **Pediatric palliative care** (2).
- **Family-centred care** (1).
- **Caring for the healthcare providers** (1). “In cancer, children are going to die....How do we care for ourselves and the patients, while we are grieving the loss of the children? It was a very enlightening session, pulling from each other to see how we can cope.” – Lead Nurse

Opportunities for improvement

Knowledge to practice

Although two partners indicated that they were considering how to implement practices they learned from nursing rounds, it is **unclear how much the rounds are currently driving supportive care**. Actual impact remains to be seen.

Attendance

The most commonly cited challenge was the same as for the case consultation rounds: **low attendance (7)** due to busy schedules. **Popular sessions are repeated**, which mitigates this problem. Partners suggested raising attendance by video-recording rounds so that they can be watched afterwards (1), offering the information in hard copy (1), and offering certificates for attendance (1). However, it is important to note that all of these measures are already in place. Therefore, SickKids could increase attendance simply by **raising awareness of alternate methods of participation that already exist** (watching video recordings, reading hard copies) and **making sure that all partners know that certificates of attendance are offered**.

Leadership by nursing graduates

When the first cohort of **students from the nursing program** returns to their home countries, they can begin to lead rounds (1).

Successes

Progress to date

The program is up and running and accredited (1), with the **first cohort of 13 students** having started classes in August 2016. An additional 15 students will form the second cohort. The students come from **all 6 countries** involved in SCI.

Building capacity

Stakeholders agreed that the program will **increase nursing capacity** in SCI countries (6): there has never before been a pediatric haematology/oncology nursing program in the Caribbean (1). Stakeholders expect the graduates to return to their countries with **greater respect and confidence** as an **integral part** of a multidisciplinary care team (2): “Nurses can speak with authority and are now really part of the team.” – Nurse

The program employs **adult learning principles**, such as the integration of theory and practice and the inclusion of hands-on practical exercises (1).

Creating teachers and leaders

The program uses a **train-the-trainer** model, so that the skills and knowledge that are gained will continue to build once the graduates return to their home institutions (4). Stakeholders expect the graduates to **spread the knowledge** they have gained by training others in their institutions (4) and **leading nursing rounds** (1). They foresee these nurses becoming **champions and advocates** for the cause of childhood cancer and blood disorders in their countries (4).

The program has a side benefit of **building relationships among nurses** across countries (2).

“We now have nurses who can speak with authority at the national level about children with cancer.” – Nurse

Opportunities for improvement

Continued monitoring of impact

The program has just begun and the first cohort has not yet graduated. As a result, it is **not yet clear** how much capacity the program will build, how much that capacity will build on itself through the train-the-trainer approach, and to what extent the graduates will become mentors, champions, and advocates.

Ensuring sustainability

The program needs **permanent, dedicated faculty** in order to ensure sustainability, but there have been challenges in securing this (2). Stakeholders suggested expanding the program into a **general pediatric nursing program** to ensure its continued existence (3).

Legislative challenges

When they return to their countries, graduates **may not be legally allowed** to use some of the skills they developed (1). One partner pointed out that, in Jamaica, **chemotherapy can be handled only by physicians**, not nurses, regardless of their training. **Legislation is needed** to fix this problem (1).

Brain drain

“**Brain drain**” of nurses away from their home countries is a concern (3).

Research, scholarly activities, and advocacy

Introduction

The research, scholarly activities, and advocacy focus area works to spread knowledge and raise awareness both regionally and internationally regarding pediatric cancer and blood disorders in the Caribbean. This is done collaboratively by Caribbean partners and SickKids staff via invited lectures, poster presentations, and peer-reviewed publications in regional and international venues. (n=19/22)*

“[Haematology/oncology] is a low-attention issue unless you’re directly dealing with a dying baby with cancer. SCI has turned the light on to childhood cancer and haematology. All of these knowledge translation activities have raised the awareness, and made a big impact on nursing students and medical students and even people outside of pediatrics.” – *Lead Physician*

Spreading knowledge and
awareness

*These numbers indicate the number of stakeholders who provided statements on this topic. For the purposes of this count, each focus group is considered one stakeholder.

Successes

Progress to date

As of March 2016, SCI stakeholders have disseminated information on childhood cancer and blood disorders in the Caribbean—and shared the goals, processes, and impacts of SCI— through **15 invited lectures, 10 posters and abstracts, and a peer-reviewed article**. Considering that most of a project’s knowledge translation comes at the end, having completed this number of scholarly activities by this point is impressive (1).

Wide audiences

These products have reached wide audiences, appearing in both **regional venues** (Caribbean Nurses Organization, Caribbean Association of Oncology and Hematology) and **international venues** (*Studies in Health Technology and Informatics*, International Counsel of Nurses, Canadian Conference on International Health, Global Telehealth Conference, International Society of Paediatric Oncology [SIOP] Annual Meeting).

Increased knowledge

Stakeholders report that these activities **increased knowledge (6)** among the partners themselves (4) as well as other researchers (2). One SickKids stakeholder pointed out that existing literature on pediatric oncology/ haematology in the Caribbean is scarce.

Enhanced advocacy and awareness

Stakeholders feel that scholarly activities have **boosted advocacy and awareness-raising efforts (5)** by giving SCI regional and international exposure (4), raising awareness of the childhood cancer and blood disorders (1), and serving as a model for health partnerships in resource-constrained settings (1).

Career advancement for partners

A side benefit of the research and scholarly activities is career advancement for partners (5), especially those who work in academic settings and are expected to engage in scholarly activities (4). A Lead Physician expressed appreciation that authorship includes everyone who contributed.

Opportunities for improvement

Broadening audiences

Stakeholders want to **continue producing lectures and publications (2)**, and to target them at **Caribbean governments and families**, not just researchers (2).

Expanding research

Research projects on family-centred care (1), haemophilia (1), and the impact of the nursing program (1) were proposed. As described in more detail in the section on local oncology databases, **abundant research opportunities will emerge** as the REDCap databases are populated and mined.

Local ownership

Stakeholders both at SickKids and in the Caribbean look forward to more of the **research responsibility and ownership being handed over to the Caribbean partners (2)**.

Measuring impact

One Lead Physician said, “we want to see impact, not just the publication itself.” But the actual impact of these research and scholarly activities is **not yet known (3)**. **Tracking citations** will be one method to estimate the academic, though not the public, influence of these products.

Sickle Cell Disease

Introduction

Sickle Cell Disease is a genetically based blood disorder that causes red blood cells to form into crescent shapes, resulting in severe anemia. If left untreated, Sickle Cell Disease causes children to have painful “crises,” strokes, and infections, and can result in early mortality. The recessive gene that causes Sickle Cell Disease is most often found in people of African descent, making it the most common genetic disorder in the Caribbean.

The Sickle Cell Disease focus area has worked towards the goal of universal screening of newborns for the disease, so that affected children can be treated as early as possible, rather than waiting until they present with life-threatening infections. Screening involves collecting blood samples (such as from the umbilical cord) and using high-performance liquid chromatography (HPLC) to test for the mutated gene; if the result is positive, isoelectric focusing is then used to confirm the diagnosis. SCD has worked to build HPLC and isoelectric focusing facilities within the region, as well as to pilot a system in which blood samples are shipped from countries without testing facilities to those countries that do have such facilities. (n=15/22)*

Tackling a devastating blood disorder

“If we can diagnose even just one case [of Sickle Cell Disease] a year, diagnose it early and prevent complications for that patient, then that will be worth it.” – *Lead Physician*

*These numbers indicate the number of stakeholders who provided statements on this topic. For the purposes of this count, each focus group is considered one stakeholder.

Successes

Progress to date

SCI has **increased access** to newborn screening for Sickle Cell Disease (4). A lab at the Tropical Medicine Research Institute in Kingston is now fully equipped with HPLC and isoelectric focusing facilities to process Sickle Cell Disease tests for newborns. As of March 2016, it has processed over **25,000** tests for newborns in Jamaica and over **900** tests for newborns in St. Lucia.

As a result, newborn screening for Sickle Cell Disease is now **island-wide in Jamaica (2)**. St. Lucia had achieved near-universal newborn screening, but using an outdated testing method. A pilot program is now underway to determine the efficacy and feasibility of **switching to a more up-to-date testing method (HPLC and isoelectric focusing) in St. Lucia**, by sending blood samples to the lab in Jamaica for processing (2).

Faster and more accurate diagnosis

The new testing method **increases both the accuracy and speed** of diagnosis (1). According to one partner, “I get the child in a quarter of the time that it used to take. [The old] screening method took 4 to 6 weeks, while the new [method] takes just 5 to 15 days. It’s a huge, huge difference.”

Improved outcomes

Early and accurate diagnosis will **improve outcomes (5)** by making sure that children with Sickle Cell Disease are given antibiotics and immunizations against the infections that they are prone to, and hydroxyurea to prevent sickling of blood cells. This can **prevent death and disability (2)**.

Opportunities for improvement

Expanding screening in Jamaica

Jamaica has not yet achieved completely universal newborn screening (3). One partner estimated that coverage was at 95%. Children born in smaller private institutions may not be screened (2). Closing this gap requires outreach to smaller institutions (1).

Expanding screening in St. Lucia

St. Lucia’s screening project is only a pilot (1); most newborns in St. Lucia are **still tested with the older method, which is slower and less reliable**. Stakeholders expect the pilot to demonstrate that shipping blood samples for processing in Jamaica is a cost-effective way to ensure accurate early diagnosis (4). Once this is achieved, the pilot can be **scaled up**.

Expanding screening in other countries

In other SCI countries, **individuals may not be diagnosed** with Sickle Cell Disease until they present with infections, “crises,” and other painful and potentially fatal complications of the disease (1). These countries have **varying levels of readiness** to institute universal newborn screening by shipping samples to the lab in Jamaica (9). Barriers include:

- **Costs (3)**. In the words of a nurse, screening “is cost effective but that doesn’t mean cheap.”
- **Stigma** associated with the disease (1)
- A perception that the disease should **be identified symptomatically**, without screening (1)
- The difficulties of **change management (1)**
- The challenge of **shipping samples to Jamaica (1)**, which can be more difficult than shipping them to the US or Canada (1).

Stakeholders look forward to the results of the St. Lucia pilot project, so that they can **prove to their governments** that universal screening of newborns by sending blood samples to Jamaica is a cost-effective approach (4).

“I’d like to see that every baby born in Caribbean would be screened and those with Sickle Cell Disease would be in a clinic by four months.” – Partner involved in Sickle Cell Disease

Unanticipated impacts

Positive impacts

Stakeholders pointed out a **variety of positive unanticipated impacts** of SCI. The initiative has:

- **Conferred economic benefits** on partner institutions (8). This has come about due to **new fundraising opportunities** (4): SCI has helped to make the region **more competitive in securing grants** (2) (such as the Novo Nordisk grant for a project on haemophilia [2]) and **attracting private sector funding** (1). Economic benefits also come from **cost-savings** (4) from free diagnostic services (1) as well as reduced medication prices that SickKids personnel helped to negotiate (2).
- **Created enduring relationships, partnerships, and communities of practice** (7). These are not only North-South relationships (i.e. between SCI countries and SickKids) (2) but also, crucially, South-South relationships (i.e. between SCI countries) (7). A Lead Physician said, “This initiative has made us talk to each other! Normally I wouldn’t be talking to people in [other SCI countries]....And that connection will continue.”

“What SCI has done is brought us together as a region so that we have each other as supports.” – Nurse

“The partners have really used the momentum of the project to get themselves in front of the decision makers...to become change agents.” – SickKids stakeholder

- **Boosted advocacy efforts** (6). Partners have used the momentum of SCI and the prestige of SickKids to bend the ear of political leaders. “Having the support of SCI means you get more kudos from governments. It helps to get people in authority to listen to you a little bit differently, rather than having each island doing it on its own.” – Lead Physician
- **Created a model that can be used for other public health initiatives** (4). This includes childhood cancer/blood initiatives in other resource-constrained parts of the world (4), and other healthcare partnerships in the Caribbean (2). As one partner noted, “Most people with Sickle Cell Disease are born in Africa and Asia...We can pioneer approaches here and then they can be applied elsewhere.” One partner pointed out that the Caribbean is a good place to pilot such projects, because it is a relatively *stable* region, has great *need*, and has a *sizeable population* when several countries are combined.
- **Created facilities with spill-over benefits** (4). In particular, the teleconferencing facilities are being used for telemedicine activities other than just SCI nursing rounds and case consultation rounds (3).
- **Created unanticipated clinical benefits** (3) including increased access to medication (2) and the creation of a pediatric ward (1).
- **Made childhood cancer a more comfortable subject** (2). “[Nurses] had a fear of cancer in children, a fear of the drugs and administering the drugs. Now it’s more of a conversation that people are comfortable with.” – Lead Physician.

Negative impacts

No negative impacts of SCI were noted.

Implementation and project management

Successes

Motivating stakeholders

A SickKids stakeholder described the project management team as highly effective: “I think there’s a lot of heavy lifting and nagging to make sure that things get done and people do what they said they would do, and **it’s the project team that makes that happen** – not just for the Caribbean partners but also the Canadian ones. There’s a few people who push things forward....We all need people to do that nagging and pushing and motivating.”

Transparency and accountability

The initiative’s logic model, dashboard, annual progress reports, and governance structure are **closely aligned with each other**: each is arranged according to the **six focus areas** (clinical care; diagnostic services; local oncology databases; nursing; research, scholarly activities, and advocacy; and Sickle Cell Disease). This is a great asset to SCI’s **transparency**, rendering the project’s goals and activities **exceptionally clear** to funders, evaluators, and the public. It also indicates a **strong consensus on the project’s vision**.

Keeping stakeholders informed

SickKids stakeholders are doing a good job of **keeping the partners informed** (1). Quarterly e-Updates and Dashboard Reports are **opened by nearly half of stakeholders** (41% and 48%, respectively).

Opportunities for improvement

Project management in the Caribbean

One SickKids stakeholder pointed to a need for a **“mirror” project management team** on the Caribbean side; currently, it’s being coordinated on “borrowed time.”

Expanding partnerships

Two SickKids stakeholders wanted the project to develop **wider Caribbean partnerships**, linking to region-wide bodies such as CARPHA and CARICOM. This could include expanding the project to other countries (1).

Focusing efforts

One SickKids stakeholder worried that the project was pursuing **too many priorities**: “How do you have broad impact without just running after 50 goals at the same time? People sometimes say, “Hey, we haven’t looked at *that* disease!” That’s all very well intentioned, but we have to look at the limited resources in both the Caribbean and here at SickKids. We do prioritize – the six working groups are our priorities – but I joke sometimes that at every SCI meeting I go to, there’s something new going on I hadn’t heard about before.”

Staying in touch

The proportion of stakeholders who open the e-Updates and Dashboard reports has **not quite reached the targets** (45% and 53%, respectively).

Sustainability

Challenges

Stakeholders recognize the importance of **ensuring SCI's successes continue after the funding stops** (8). However, they pointed to numerous challenges: **resources are scarce** in the Caribbean (3), government **priorities can shift** (2), and losing SickKids means having **no project management team** to move things forward (2).

Stakeholders worried in particular about the sustainability of:

- **Nursing** (4), especially given the potential for “brain drain” of the nursing program graduates as they are hired in other countries (3).
- **Local oncology databases** (4), given that the data managers are funded by SCI (3) and databases do not sound exciting to potential funders (1). (One partner mistakenly believed that REDCap would cost money after SCI ended.)
- **Diagnostic services** (3). The costs for flow cytometry will need to be covered locally when SCI ends (3). Furthermore, local labs are having trouble gaining certification (1). Currently, sending samples to SickKids provides a back-up when local machines break, but this will not be the case when SCI is done (1).

Enablers

Despite these challenges, stakeholders are **reasonably optimistic** about sustainability (7). They pointed to the following enablers of sustainability:

- **Significant human capital has been built** (5). “We’ll have trained 4 physicians, 28 nurses, 1 lab technician, 1 surgeon. For a 5 year project to have built up that kind of human capital in a region, that very specialized knowledge, that’s [huge]” – SickKids stakeholder
- **The Caribbean community of practice** that has developed will endure (3)
- Local oncology databases require only **part-time staff** (3)
- The region now has its own **flow cytometry capabilities** (3)
- Fellowships and training have created **champions for the cause** (2): “[Name] has become an advocate. There is no cost you can put on that, not even a million Canadian dollars.” – Lead Physician
- Guidance documents (1), the nursing program (1), and the telemedicine facilities (2) are **here to stay**.
- **Local governments have buy-in** (2), since childhood cancer “pulls at the heartstrings” (1).

“I’m not fooled that SickKids will be here forever. Building capacity is about helping us become self-sufficient.” – Physician

Opportunities

In order to ensure sustainability, stakeholders emphasized the need for:

- **Obtaining buy-in from the highest government levels** (9) so that they can fund the activities after SickKids leaves. This can be done by using data from the local oncology databases to prove the achievements of SCI and their cost-effectiveness (3). One stakeholder emphasized the importance of continual advocacy, even after MOUs are signed, because political parties come in and out of power.
- **Fundraising** (6), especially through public-private partnerships (3). “In a few hands, there is great wealth in those countries.” – SickKids stakeholder
- **Having a Phase II of SCI** (5) to consolidate the project’s gains.
- **Grooming champions for the cause** (4), especially by mentoring nursing program students to become advocates and leaders (3).
- **Expanding linkages to the entire Caribbean region** (4), and developing a regional cancer and blood disorders strategy (1)
- **Ensuring the nursing program continues** by making it a general pediatric nursing program

Clarifying priorities and values

Stakeholders disagree about whether the best strategy is to **focus on childhood disease** (since it “pulls at the heartstrings”) (2) or to make it about **increasing capacity for adult cancer too** (since it is more cost effective) (3). There is also disagreement about **whether the end goal should be total regional self-sufficiency**, or a continued link with the US and Canada.

Conclusion

Conclusion

Key successes of the initiative

SCI is a **well functioning, highly valued project that is making strong progress towards its intended goals**. Among the initiative's most impressive accomplishments to date are that it has: established a commitment among all partners to reduce treatment-related mortality by a third; greatly expanded access to diagnostic services and reduced delays in treatment; made the countries more competitive in securing grants; and built strong South-South communities of practice and reduced professional isolation.

SCI's success is based on the dedication of stakeholders, the responsiveness of SickKids staff to the needs and ongoing feedback of partners, and a deep understanding that solutions in the Caribbean cannot, and should not, be identical to solutions in Canada. Extensive upfront work to forge individual and institutional partnerships has paid rich dividends in the form of strong trust and a shared vision.

The **responsive, collaborative nature of the project** has allowed a number of potential stumbling blocks to be avoided early on. For instance, concerns around data privacy were headed off by ensuring from the beginning that the databases would be owned by hospitals; the potential incompatibility of guidance documents with the resources available in the Caribbean was mitigated through the co-authorship approach; technological constraints in the nursing rounds and case consultation rounds were anticipated and mitigated by installing up-to-date telemedicine facilities in each site before the rounds began; and potential challenges in establishing regional capacity for flow cytometry were allayed by allowing samples to be shipped to SickKids (rather than an in-region facility) as a stopgap measure.

Priority areas for improvement

Other than various incremental improvements suggested in individual sections of this report, **the largest opportunity for improvement is to strengthen sustainability**. Establishing a truly sustainable regional haematology/oncology system—one that will survive the eventual withdrawal of SickKids' substantial funding, project management, and prestige—in a mere five years is a tall order. Planning for that day requires securing local sources of funding and identifying Caribbean champions to carry the mantle of project management and advocacy, and all of this must be done before the project ends.

Carrying the project forward requires **two conversations on fundamental issues of vision and values**:

The first conversation is on whether tackling childhood cancer and blood disorders should be pursued as **a cause unto itself**, or as **part of a wider mission** to address cancer and blood disorders in all ages or improve public health systems overall. Framing it as a cause unto itself attracts widespread support because it “pulls at the heartstrings,” but may be inefficient given the small number of cases of childhood cancer and blood disorders per year. Framing it as part of a wider mission may weaken the moral appeal, but foster more cost-effective solutions with wider benefits.

The second conversation is on **whether regional self-sufficiency for pediatric haematology/oncology is a need-to-have, or only a nice-to-have**. Developing in-country capacity is clearly a valued goal, but some stakeholders suggested that an ongoing relationship between the partner countries and SickKids (or other North American institutions) is not necessarily a bad thing, and should not be rejected out of hand. A compromise between the two positions would be to institute a Phase II of SCI, with the understanding that more time and support may be needed to consolidate the project's gains, but also that the partner countries cannot depend on SickKids in perpetuity.

Appendices



SCI Q4 Dashboard Report (January - March 2016)

Working Group	Activity	Process Indicators	Q4 (2016) Jan - Mar	Total Current	Total Forecast	
Nursing	Patient Care Education Rounds	# of rounds held	1	12	24	
		Total attendance	11	382		
		Evaluation response rate	36%	72%	100%	
	Participant satisfaction	4.75	4.24	5/5		
Clinical Care	<p>Q4 Nursing Updates:</p> <ul style="list-style-type: none"> Applications for the nursing education program have been sent to all partner institutions One Patient Care Education Rounds was held in Q4 on "Caring for the Care Provider" and a repeat session will be held on this topic in early May <p>Case Consultations</p> <ul style="list-style-type: none"> # of cases submitted # of cases presented # of rounds held # cases requiring diagnostic imaging # cases requiring pathology # supportive care completed # supportive care implemented # clinical care completed # clinical care implemented # of UWIDEC Rounds # ASPHO annual memberships # CME grants # Other CME activities <p>Paediatric Haematology/Oncology Guidance Documents</p> <ul style="list-style-type: none"> # clinical care completed # clinical care implemented <p>Continuing Medical Education Activities</p> <ul style="list-style-type: none"> # ASPHO annual memberships # CME grants # Other CME activities 		14	102		
				7	57	110
				4	32	55
				13	34	
				7	21	
					5	5
				TBD	0	5
				1	1	18
				0	0	18
				1	12	18
				N/A	20	42
				N/A	7	14
		0	1			
Local Oncology Databases	<p>Q4 Clinical Care Updates:</p> <ul style="list-style-type: none"> The first clinical care guidance document has been completed on the topic of "Brain Tumor Practical Algorithm" On track to develop 4 more clinical care guidance documents (3 LL, 1 ST, 1 BT) by the Annual General Meeting (AGM) 4 Case Consultation Rounds were held; 14 cases were submitted and 7 were presented Local implementation of 5 supportive care guidance documents will be presented at the AGM by each site Coordinator at Bustamante started work in February Participated in 1 UWIDEC Rounds with Trinidad on April 5, 2015. Dr. Julie Upton presented on "Pediatric Thymoma" <p>Implementing databases</p> <ul style="list-style-type: none"> # of new patients registered # of hired and trained staff 		124	325	7	
Diagnostic Services	<p>Q4 Local Oncology Databases Updates:</p> <ul style="list-style-type: none"> Working group continues to meet online every 6-8 weeks Goal to enter all 5-year retrospective data from 2011 - 2015 for presentation at AGM RedCap has been updated to send reminder e-mails to data managers at prescribed time intervals Data Base manager at Bustamante started work in February. All data managers are now in place <p>Enhancing laboratory services</p> <ul style="list-style-type: none"> # new immunophenotyping tests at UHWI # new immunophenotyping tests at SickKids # of laboratory trainees 		3	16	240	
				8	52	240
				0	21	
Sickle Cell Disease	<p>Q4 Diagnostic Services Updates:</p> <ul style="list-style-type: none"> Support for cytogenetics capacity building for UHWI continues Planning continues for immunophenotyping at NPHL <p>Establishing a Newborn Screening (NBS) program</p> <ul style="list-style-type: none"> # of St. Lucia tests at central lab (TMRI, Jamaica) # of Jamaica tests at central lab (TMRI, Jamaica) <p>Q4 Sickle Cell Disease Updates:</p> <ul style="list-style-type: none"> TMRI has created a QI review process to cross-reference results with St. Lucia samples In January 2016, SCI participated in the CAREST SCD conference in Kingston, Jamaica, which included physicians and nurses from all 7 sites and a keynote address by Dr. Isaac Odame Continuing to assess involvement in NBS program in St. Vincent <p>Building research capacity</p> <ul style="list-style-type: none"> # invited lectures # publications # abstracts/posters 		44	600	20708	
				4885		
				0	15	
Research and Scholarly Activities	<p>Q4 Research and Scholarly Activities Updates:</p> <ul style="list-style-type: none"> Preparation for SIOp abstract submission <p>Facilitating, monitoring and evaluating project activities and deliverables</p> <ul style="list-style-type: none"> % Quarterly e-Update opens % Quarterly Dashboard Report opens 		41%	41.1%	100%	
				44%	48.0%	100%
Project Management	<p>Q4 Project Management Updates:</p> <ul style="list-style-type: none"> Dates and location have been secured for the 2016 SCI Annual General Meeting, taking place in Barbados May 16 & 17 by invitation 					

Appendix B: Focus group guide

Warm-up

Please tell me your name and how you're involved in SCI.

Clinical rounds

Let's talk about some of the specific goals of SCI. As you know, one of those goals is to increase the use of specialized knowledge related to pediatric cancer and blood disorders. To achieve this, as of March 2016 SCI has held:

- 12 nursing rounds with close to 400 people participating in them; and
- 32 clinical care rounds in which 57 cases have been discussed

Do you find any of these types of rounds to be an effective way for clinicians to access specialized knowledge?

Probe: Can you comment specifically on the nursing rounds? Clinical care rounds?

Probe: Have you seen any of these types of rounds result in any changes in clinical practice (explain)? Which type of rounds? Under what conditions are they useful?

How can these rounds be improved?

Probe: Can you comment specifically on the nursing rounds? Clinical care rounds? UWIDEC rounds?

Databases

Another goal is to increase the use of data to improve clinical care and decision-making. With this goal in mind, as of March 2016 SCI has:

- Implemented REDCap databases in all six participating countries
- Hired and trained 7 database managers, who have been able to register 325 new patients, and entered over 5 years of retrospective data into these databases going back to 2011

What types of uses do you see for the data generated through these databases?

Probe: What has the impact been of having this data which was not previously available?

Probe: Is this data already being used now? In what ways? Under what conditions?

Probe: How could this data be used in the future? Under what conditions?

How can these databases be improved?

Probe: What kind of information should the databases include? What challenges exist for obtaining accurate, complete, and useful data?

Diagnostic services

Another focus of SCI has been to increase access to diagnostic services. Towards this end, as of March 2016 SCI has:

- Trained 21 laboratory trainees
- Processed 68 new immunophenotyping tests at SickKids and UHWI
- Established a newborn screening program for Sickle Cell Disease that has processed over 21,000 tests for babies in Jamaica and St. Lucia

Do you feel that diagnostic services have improved as a result? Please explain.

What impact have these newly available diagnostic services had?

Probe: Has the effort to increase access to diagnostic services resulted in bidirectional learning – from SickKids to the Caribbean partners and vice-versa?

Probe: What impact have they had on individual patients? Clinicians? Hospitals or other healthcare facilities? The healthcare system in particular countries? The Caribbean region more broadly?

How could these diagnostic services be improved?

Probe: What challenges remain to screen newborns for Sickle Cell Disease?

Probe: What challenges remain in making immunophenotyping accessible?

Knowledge translation

SCI is also working to promote knowledge translation related to pediatric cancer and blood disorders. As of March 2016, SCI stakeholders have

- Given 15 invited lectures, 5 poster presentations, and published a peer-reviewed journal article
- Created opportunities for sharing evidence-based practice through 44 clinical care and nursing rounds
- Created 5 supportive care guidance documents
- Begun to create a series of clinical care guidance documents

What impact have these knowledge translation activities had on the capacity of Caribbean countries to provide care for children with cancer and blood disorders?

Probe: Have the clinical care guidance documents been useful? Are they being used? Why or why not?

How could these knowledge translation activities be expanded or improved?

Probe: What challenges exist in sharing useful evidence throughout the region?

Unanticipated impacts

Now let's talk about other impacts of SCI, ones which weren't planned for or expected, but ended up happening. These could be either positive or negative.

What are some of the unanticipated impacts of SCI so far?

Probes: For instance, did new partnerships develop that you didn't expect? Has SCI led to bidirectional learning –from SickKids to the Caribbean partners and vice-versa?

Sustainability

As you know, a question on a lot of people's minds is what will happen after the project concludes in 2018. Everyone wants the successes to continue for many years afterwards. So with that in mind...

What processes and structures are required to sustain SCI's successes beyond the project funding period?

Wrap-up [ask only if there is time remaining]

Reflecting on SCI implementation in the last few years, are there opportunities to enhance key areas such as partnerships or processes?

Thinking about everything we have talked about so far today, what would you say are the most significant impacts that SCI has had?

Probe: What are the impacts on individual patient care? Hospitals and other healthcare facilities? Health systems of entire countries or the wider Caribbean region?

Probe: Under what conditions have these impacts been achieved?

Is there anything else that anyone would like to say about the SCI project?

Warm-up

Please tell me a bit about your role within the SCI.

Clinical rounds

As you know, SCI is working to increase local capacity to develop and apply specialized knowledge related to pediatric cancer and blood disorders. To support this, as of March 2016 SCI has held:

- 12 nursing rounds with close to 400 people participating in them;
- 32 clinical care rounds in which 57 cases have been discussed; and
- 12 UWIDEC rounds

Do you find these rounds to be an effective way for clinicians to access specialized knowledge? Why or why not?

Probe: Can you comment specifically on the nursing rounds? Clinical care rounds? UWIDEC rounds?

Probe: Have you seen any of these types of rounds result in any changes in clinical practice (explain)? Which type of rounds? Under what conditions are they useful?

How can these rounds be improved?

Probe: Can you comment specifically on the nursing rounds? Clinical care rounds? UWIDEC rounds?

Databases

SCI is also working to increase the use of data to improve clinical care and decision-making. With this goal in mind, as of March 2016 SCI has:

- Implemented REDCap databases in all six participating countries
- Hired and trained 7 database managers, who have been able to register 325 new patients, and entered over 5 years of retrospective data into these databases going back to 2011

What types of uses do you see for the data generated through these databases?

Probe: What has the impact been of having this data which was not previously available?

Probe: Is this data already being used now? In what ways? Under what conditions?

Probe: How could this data be used in the future?

How can the databases be improved?

Probe: What would make the databases more useful to you or your colleagues? What kind of information should the databases include? What challenges exist for obtaining accurate, complete, and useful data?

Diagnostic services

Another focus of SCI has been to increase access to diagnostic services. Towards this end, as of March 2016 SCI has:

- Trained 21 laboratory trainees
- Processed 68 new immunophenotyping tests at SickKids and UHWI
- Established a newborn screening program for Sickle Cell Disease that has processed over 21,000 tests in Jamaica and St. Lucia

Have you experienced (or observed) any improvements to diagnostic services? Please explain.

What impact have these newly available diagnostic services had?

Knowledge translation

SCI is also working to increase knowledge translation (the dissemination of evidence) related to pediatric cancer and blood disorders. In this area, as of March 2016 SCI stakeholders have:

- Given 15 invited lectures, 5 poster presentations, and published a peer-reviewed journal article
- Created opportunities for sharing evidence-based practice through 44 clinical care and nursing rounds
- Created 5 supportive care guidance documents
- Initiated production of a number of clinical care guidance documents

What impact have these knowledge translation activities had on the capacity of Caribbean countries to provide care for children with cancer and blood disorders?

Probe: Do you use the guidance documents? In what ways? Under what conditions?

Probe: Have the clinical care and nursing rounds proven to be useful to you? In what ways? Under what conditions?

How could these knowledge translation activities be expanded or improved?

Probe: What challenges exist in sharing useful evidence throughout the region? What evidence would be most useful to you in your own work?

Unanticipated impacts

Programs often have unanticipated impacts that weren't planned for or expected, but ended up happening. These can be either positive or negative.

What are some of the unanticipated impacts of the SCI so far?

Probes: For instance, did you develop new partnerships that you didn't expect? Did the SCI lead to your organization receiving more resources, either money or in-kind?

Implementation [ask only of internal stakeholders]

Reflecting on SCI implementation in the last few years, are there opportunities to enhance key areas such as partnerships or processes?

Sustainability

The SCI is scheduled to conclude in 2018, but of course it is hoped that the gains that it has achieved will be continue for many years afterwards.

What processes and structures are required to sustain SCI's successes beyond the project funding period?

Wrap-up [ask only if there is time remaining]

Thinking about everything we have talked about so far, what would you say are the most significant impacts that the SCI has had?

Probe: What are the impacts on individual patient care? Hospitals and other healthcare facilities? Health systems of entire countries or the wider Caribbean region?

Probe: Under what conditions have these impacts been achieved?

Is there anything else you'd like to tell me about the SCI project?

Sampling approach

Focus group participants and interviewees for the SCI midterm evaluation will be selected through **purposeful sampling**. Purposeful sampling is a kind of nonprobability sampling in which study participants are chosen according to the investigator's criteria rather than randomly (Pedhazur and Schmelkin 1991: 320-1). Purposeful sampling allows researchers to solicit the desired information from the informants most able to provide it (Patton 1990: 169). For this reason, purposeful sampling is often preferred in qualitative studies when the sample must be small due to resource constraints (Pedhazur and Schmelkin 1991: 321).

Purposeful sampling will be performed according to the following two criteria:

1. Maximum variation. The interview sample will include diverse *occupations* (physicians and nurses), *roles* (administrative and clinical), and *countries/sites* (at least one invitee from each of the seven sites in the six Caribbean countries taking part in SCI). The focus group sample will include members of the SCI Executive Committee, Steering Committee, Working Groups (including all six focus areas), and Project Management Team (a variety of roles). Maximum variation sampling ensures that perspectives are heard from a wide variety of stakeholders; the central themes that emerge are those that cut across a large proportion of participant or program variation (Patton 1990: 172).

2. Political important cases. Within the variation described above, priority will be 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: 180).

When multiple individuals fit the above criteria equally, the invitee will be chosen at random, and those not chosen (but representing similar characteristics) will form a backup pool of potential invitees, should the first invitee decline to participate.

Sample size

The available resources allow for 20 interviews to be conducted. The interview sample will include more than this number (oversampling) to ensure that 20 willing interviewees can be found, given that some individuals may decline to participate in the study.

The available resources allow for 2 focus groups to be conducted. Each focus group should include 6-8 participants, as is considered best practice in focus group design (Crabtree and Miller 1999: 118). Oversampling will be performed to ensure that 6-8 willing participants can be found for each focus group.

References

Crabtree, B.F. and W.L. Miller 1999. *Doing qualitative research*. Thousand Oaks, CA: Sage.

Patton, M. 1990. *Qualitative evaluation and research methods*. Beverly Hills, CA: Sage.

Pedhazur, E.J. and L.P. Schmelkin 1991. *Measurement, design, and analysis: an integrated approach*. Hillsdale, NJ: Lawrence Erlbaum.

INFORMATION SHEET: MIDTERM EVALUATION OF THE SICKKIDS-CARIBBEAN INITIATIVE

Purpose

The SickKids-Caribbean Initiative (SCI) was launched in 2013 with a goal of building sustainable local capacity to diagnose, treat and manage pediatric cancers and blood disorders in six Caribbean countries (The Bahamas, Barbados, Jamaica, St. Lucia, St. Vincent and the Grenadines, and Trinidad & Tobago). SCI is working to build capacity over a five-year period (2013-2018) by partnering health care specialists at SickKids in Toronto with their counterparts in the Caribbean and supporting working groups in six areas of focus. Objectives include:

- Improving the clinical management and treatment of paediatric cancer and blood disorders;
- Providing opportunities for training and education in the areas of nursing, pharmacy, pathology, laboratory and medicine;
- Establishing best practices and improving health outcomes through the development of local hospital-based oncology databases (REDCap); and
- Establishing an integrated and sustainable communication structure for bidirectional education amongst local partners (e.g., telemedicine equipment enhancements and regular Case Consultation Review Rounds).

The Centre for Global Child Health at the Hospital for Sick Children (SickKids) has engaged Cathexis Consulting, a Toronto-based evaluation firm, to conduct a midterm evaluation of the SCI between September and November 2016. As part of this evaluation, Cathexis Consulting is conducting 20 interviews to better understand:

- SCI's accomplishments to date, particularly in terms of:
 - increased use of specialized knowledge (e.g., application of best practices in patient management),
 - increased use of data to support clinical care and decision-making (e.g., use of data in REDCap),
 - increased availability and access to diagnostic services (e.g., enhancing and expanding capacity of regional laboratory services), and
 - increased knowledge translation and dissemination of evidence-based practice (e.g., publications, presentations and locally adapted clinical care guidance documents);
- The factors that led to these accomplishments;
- Any unanticipated impacts or effects of the program;
- Areas for potential improvement and ways to increase impact; and
- How gains can be sustained beyond the project funding period.

Information from these interviews will supplement the monitoring data that has been collected throughout the SCI project, and provide a deeper understanding of the impact of SCI and opportunities to strengthen the initiative over the next year and a half.

Participant involvement

What is involved: You will be invited to participate in an individual interview via Skype lasting 30-45 minutes. The interview will be conducted by a trained interviewer from Cathexis Consulting who will ask questions about your perception of SCI's accomplishments, success factors, opportunities for improvement, unanticipated impacts, and sustainability. Your interview will be audiotaped with your permission. You will have the opportunity to review, validate, and (if necessary) correct the summary notes taken during your interview.

Voluntary participation: Your participation is completely voluntary and will in no way affect your relationship with SCI, the Centre for Global Child Health, or the SickKids Foundation. You are free to refuse participation or to withdraw from the evaluation at any time with no impact on your work or professional status.

Confidentiality: Your evaluation data, including the audiotape, will be handled as confidentially as possible, and stored in a secure, password-protected location at Cathexis Consulting. Only Cathexis Consulting staff (who are external to SickKids) will have access to the detailed interview notes. Cathexis Consulting will summarize feedback from all interviews into a summary report that will be presented to the SickKids Foundation and the Centre for Global Child Health. The audiotape will be destroyed after it is used for note-cleaning. Your name will not be included in any reports or presentations. However, given the small number (20) of stakeholders to be interviewed and the relatively unique role each person plays, complete anonymity cannot be guaranteed.

Potential harms or inconvenience: Participation in the evaluation involves taking some of your time to discuss your thoughts and perceptions with the interviewer. Although your name will not appear in any report or presentation, it is possible that an individual could identify you in the report or presentation, given the small number of interviewees and the relatively unique roles that they play within SCI.

Benefits: You will not benefit directly from participating in this study. The results of this evaluation will help to increase understanding of what is happening and what can be done to maximize the impact of the SCI in order to create the best possible outcomes for children living with cancer and blood disorders in the Caribbean.

Outcome and feedback: You may request a copy of the final report. You will have access to your own interview notes. Results will be used to inform continued development of SCI.

If you have any questions about this study, please contact Margaret Manley-Kucey at margaret.manley@sickkids.ca or 1-416-813-8761.