Background

Over 80% of children with cancer live in low- and middle-income countries (LMICs); their cure rates lag far behind those of children in high-income countries (HICs). In an effort to address this survival gap, several HIC cancer centers have initiated “twinning” relationship with LMIC centers. While twinning programs have significantly improved local outcomes, their population-wide impact is questionable. National childhood cancer strategies hold the potential to increase childhood cancer cure rates across large LMIC populations, but are in place in only a handful of LMIC. Barriers to adoption include a lack of health policy, health economics and implementation research relevant to LMIC paediatric oncology.

PERCC was officially formed in June 2015 under the auspices of the Garron Family Cancer Centre (GFCC) and the Centre for Global Child Health (C-GCH), both at the Hospital for Sick Children (Sickkids), and supported through an initial grant from the GFCC. In this report, we outline PERCC’s accomplishments in the past year and future plans.

The goals of PERCC were as follows:

1. Conduct health policy and health economics research relevant to the care of children with cancer in LMICs
2. Use the results of such research to inform advocacy and policy efforts at various national and international levels

Structure

The structure of PERCC is illustrated in Figure 1. In the past year, a Scientific Advisory Board has been formed that includes: 1) Dr. James Whitlock, Director of the GFCC and Head of the Division of Haematology/Oncology at Sickkids, 2) Dr. Zulfiqar Bhutta, Co-Director of the C-GCH, and 3) Dr. Mary Gospodarowicz, Clinical Department Head at the Princess Margaret Cancer Centre and Past President of the Union for the International Control of Cancer.
The PERCC leadership includes 1) Dr. Sumit Gupta, MD, PhD, a Staff Oncologist and Clinician Investigator at Sickkids and an Assistant Professor at both the Faculty of Medicine and the Institute of Health Policy, Management, and Evaluation at the University of Toronto, 2) Dr. Avram Denburg, a Staff Oncologist at Sickkids and current recipient of a Trudeau Foundation Scholarship, and 3) Dr. Susan Horton, the CIGI chair in global health economics at the University of Waterloo and Visiting Scholar at C-GCH.
Projects

Over the past year, PERCC leadership have launched three international research projects:

1. **Cost of Burkitt Therapy, Uganda** - PERCC has partnered with an international team of collaborators at the Uganda Cancer Institute in Kampala, Uganda, and the Fred Hutchinson Cancer Research Center in Seattle, Washington, to evaluate a comprehensive treatment program for childhood Burkitt lymphoma. PERCC is leading the economic evaluation of the program, which will provide some of the first detailed data on the cost-effectiveness of treating pediatric cancer in a low-income country setting. Results of this
work will aid both institutional and national priority setting, and will contribute policy-relevant knowledge on childhood cancer treatment in diverse health system contexts.

2. Childhood Cancer Policy Mapping in Latin America, Chile - One of the outputs of our successful Forum on National Childhood Cancer Strategies in Latin America in 2015 is a collaboration between PERCC, the Union for the International Control of Cancer, Childhood Cancer International, and the Foundation Nuestros Hijos in Chile to conduct a mapping exercise of how childhood cancer is delivered, financed, and governed across Latin America. This will allow successful models to be showcased, and provide a baseline informing future childhood cancer policy efforts across the region.

3. Cost of Treating Wilms Tumour and Hodgkin Lymphoma, India – After a successful initial site visit in January, 2016, PERCC is currently collaborating with oncologists at Tata Memorial Centre (TMC), India. TMC is one of the largest cancer hospitals in the world, seeing 30,000 new patients a year, 1800 of which are under the age of 15. Together with TMC leaders like Dr. Brijesh Arora, we are piloting a study looking at the cost and cost-effectiveness of treatment for childhood Hodgkin lymphoma and Wilms tumour. The results will inform advocacy efforts both at TMC as well as at the international level, and will lead to studies of other pediatric cancers.

Publications

PERCC leaders have successfully published in the last year in journals such as Lancet, Lancet Oncology, and the American Journal of Bioethics, thereby enhancing PERCC’s reputation. A relevant list of publications is included below.


**Grants**

PERCC received a Catalyst Grant from C-CGH for $25,000 to support our collaborative study with TMC in Mumbai, India, titled “The cost and cost-effectiveness of treatment paediatric Hodgkin Lymphoma and Wilms Tumour in a middle-income country.”

**Trainees**

A key part of the PERCC mandate is to build capacity for health policy and health economics research through graduate and post-graduate level training of individuals from both HICs and LMICs. To this end, in the last year PERCC has supported two trainees:
1. Ms. Nazeefah Laher is currently completing her second year of a Masters in Public Health at the Dalla Lana School of Health at the University of Toronto. She is currently assisting with the PERCC collaborative study examining the cost of treating Burkitt lymphoma in Uganda.

2. Ms. Sarah Grace Bebenek is currently finishing her MSc in Global Health at McMaster University. Inspired by her family’s charity “Meagan’s Walk”, she is currently performing a scoping review of regional and national childhood cancer policies in LMICs.

**Other Achievements**

In order to enhance the PERCC reputation and brand, in the past year PERCC has created a website and logos. The website can be accessed at: [http://www.sickkids.ca/gfcc/research/percc/index.html](http://www.sickkids.ca/gfcc/research/percc/index.html). A screenshot is illustrated below.
In the next year, we will begin to track how often the PERCC website is accessed and from where.

**PERCC Plans for Year 2**

Over the next year, there are three main goals for PERCC:

1. **Complete the ongoing studies in Uganda, Latin America, and India**

2. **Mexico and Chile are two of the only LMICs with defined national childhood cancer plans. We are currently discussing with Ministry of Health officials in both countries the potential to conduct analyses of these policies. In Year 2, we plan on initiating a policy analysis in at least one jurisdiction.**

3. **Lancet Oncology Sustainable Paediatric Cancer Care Commission**

   The Lancet Oncology has intermittently published commissions on key aspects of global cancer care. The journal has recently agreed to support a commission looking at the burden and cost of childhood cancer care in LMICs. The commission will estimate the incidence of and mortality due to childhood cancer in LMICs both currently and projecting forward to 2035, and subsequently develop a key set of childhood cancer interventions adaptable to various resource settings with implementation and dissemination targets for the year 2035. The commission will also determine the cost of meeting the 2035 targets, their impact in terms of lives saved, and a roadmap for their achievement.

   This ambitious commission is being led by four institutions: St. Jude Children’s Research Hospital, the Dana-Farber Cancer Institute, the Harvard T.H. Chan School of Public Health, and PERCC. Dr. Sumit Gupta is one of four Commission Chairs, while Drs. Denburg and Horton are both Commissioners and Working Group Leaders. Multiple commission meetings have already been held, including a Chairs meeting in Boston in March 2016, and a Commissioners meeting in Memphis in June 2016.
The commission will be launched at the Annual World Health Assembly in May 2018 in order to directly reach an audience of Ministers of Health and policymakers. In addition, the network of institutions and individuals behind the commission will remain intact after the launch and form the “Childhood Cancer 2035 Network”, tasked with monitoring progress towards reaching the 2035 targets and with addressing any identified research, policy, or advocacy gaps. The Childhood Cancer 2035 Network represents a major opportunity for PERCC to achieve sustainability and maximize its impact.

**Conclusion**

The ultimate goal of PERCC is to improve LMIC childhood cancer outcomes by conducting health policy and health economics research that informs efforts to increase access to high quality childhood cancer care. In doing so, we also hope to establish PERCC as key international player in this field. Significant challenges remain, including achieving financial sustainability and the risks associated with better-resourced institutions entering the field. However, major opportunities also exist, including connections with various LMIC policymakers and the Lancet Oncology commission and subsequent Childhood Cancer 2035 Network. We anticipate these opportunities will continue to unfold in the coming year.
Acknowledgements

PERCC gratefully acknowledges the advice and support of both the Garron Family Cancer Centre and the Centre for Global Child Health. We also acknowledge the support we have received from Fernand Bellavance, Donna Berry, Kathryn Breckbill, Tanya Hesser, Maryam Matean and Marta Vila.