Meeting of the Pediatric Cancer Working Group

Meeting Report

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Summary of the Meeting

About 9,000 children die of cancer every year in the Americas, where cancer is the leading cause of death from disease among children under 15. In high-income countries, childhood cancer mortality has been reduced significantly and survival rates are 80% or higher. However, in Latin America and the Caribbean (LAC), pediatric cancer survival rates are significantly lower than in high-income countries, due to the gaps in access to early diagnosis and effective treatment.

In order to close this gap it is essential to foster collaboration among governments, civil society, and academic institutions—including international cooperation and South-South collaboration. This will help LAC countries to develop strategies to improve early diagnosis and treatment of pediatric cancer. Along these lines, the PAHO Pediatric Cancer Working Group is trying to improve access to care for children with cancer and to reduce inequities associated with their prognosis in LAC. The Working Group, formed in 2016 on the heels of a policy dialogue by the Union for International Cancer Control (UICC), gathered the leading pediatric oncologists from public health institutions in LAC, as well as representatives from Canada’s Hospital for Sick Children, the University of Chile, the University of the West Indies, and UICC.

To first better understand the situation, barriers, and challenges within health systems to better care for children with cancer, the Working Group is conducting an analysis of childhood cancer care and outcomes in LAC, coordinated by the University of Chile. Through a key informant survey and interviews, information is being collected on governance, financing, delivery of treatment and care, and surveillance of childhood cancer. The analysis will lead to the identification of successful models of childhood cancer care for the Region, and will form the basis upon which feasible and sustainable strategies will be suggested to improve care for children with cancer in the Region.

PAHO organized this first face-to-face meeting of the Working Group in order to discuss that analysis and determine future actions. The meeting included 33 professionals from 22 countries of the Americas, including representatives of Ministries of Health, children’s hospitals, academic institutions, and international organizations. The goal was to strengthen the group, identify possible areas of collaboration, and become an element of support for the development and improvement of pediatric cancer programs in LAC.

Represented Countries:

- Argentina
- Bahamas
- Barbados
- Brazil
- Chile
- Colombia
- Costa Rica
- Cuba
- Ecuador
- El Salvador
- Guatemala
- Guyana
- Honduras
- Jamaica
- Mexico
- Panama
- Paraguay
- Peru
- Trinidad and Tobago
- Uruguay

Represented Organizations:

- Union for International Cancer Control (UICC)
- Pan American Health Organization (PAHO)
- Hospital for Sick Children, Canada
- St. Jude Children's Research Hospital
- National Cancer Institute of the United States

The complete list of participants, as well as the detailed agenda, can be found in the Appendices starting on page 27.

PURPOSE

The two-day meeting included presentations by experts, academics, and representatives of the Ministries of Health. The participants provided information and held group discussions to:

- discuss information available and needed to complete the regional analysis on pediatric cancer care in LAC;
- identify key elements within the health care system that need strengthening to improve pediatric cancer care in LAC; and
- begin to develop recommendations for countries, and collaborating institutions, on how pediatric cancer care can be improved in LAC.

RESULTS

1. **Sharing of experiences:** Participants shared information about the pediatric cancer programs in their countries, identified the strengths and weaknesses of their health systems, and also discussed challenges and what is needed to improve outcomes.
2. **A deeper understanding of the challenges and opportunities:** Through the group discussions participants identified the specific challenges their countries face in establishing or improving pediatric cancer management programs, as well as factors that help or hinder improvement of services.
3. **Establishment of an action plan for the Working Group:** Members of the PAHO Pediatric Cancer Working Group agreed to establish a series of short-, medium-, and long-term priority actions, which are described in detail at the end of this document.
4. **Opportunities for collaboration:** The participants identified possible areas of international collaboration and committed to move forward in already existing areas of collaboration in order to improve pediatric cancer programs in LAC, including:
    a. Completing and publishing a general map of pediatric cancer in Latin America and the Caribbean.
    b. Supporting the development of evidence-based, standardized clinical protocols and promoting their use, as well as disseminating existing protocols.
    c. Supporting countries in the development of high quality pediatric cancer registries.
    d. Undertaking joint advocacy efforts to include pediatric cancer on the noncommunicable disease agenda.
    e. Publicizing and promoting use of the PAHO Strategic Fund in order to ensure access to high quality pediatric cancer drugs.
5. **Consolidation of the group:** The participants established new professional relations with their counterparts in other countries and consolidated the objectives of the Pediatric Cancer Working Group.

This document is a summary of the main issues covered during the group presentations and discussions. It also includes the conclusions and next steps identified during the meeting to establish or improve pediatric cancer programs in Latin America and the Caribbean.

ABBREVIATIONS

AHOPCA: Pediatric Hematology Oncology Association of Central America

LAC: Latin America and the Caribbean

AYUVI: “Ayúdame a Vivir” Foundation (Help Me Live)

CCI: Childhood Cancer International

CONACIA: National Board for the Prevention and Treatment of Child and Adolescent Cancer (Mexico)

IARC: International Agency for Research on Cancer

INC: National Cancer Institute of Argentina

MISPHO: Monza International School of Pediatric Hematology/Oncology

WHO: World Health Organization

PAHO: Pan American Health Organization

PAE: Specific Program of Action for Pediatric Cancer of Mexico

LMIC: Low and middle income countries

PINDA: National Antineoplastic Pediatric Drug Program of Chile

ROHA: Hospital Pediatric Oncology Registry of Argentina

RUCIA: Single Child and Adolescent Cancer Registry of Mexico

SCI: SickKids-Caribbean Initiative

SIOP: International Society of Paediatric Oncology

UNOP: National Pediatric Oncology Unit of Guatemala

UICC: Union for International Cancer Control

Day 1. Content and Summary of Presentations

WELCOME AND REVIEW OF MEETING OBJECTIVES

Silvana Luciani, Advisor for Cancer Prevention and Control, PAHO

Silvana Luciani, from PAHO's Regional Noncommunicable Diseases Program, opened the meeting by pointing out that this was the first time that a group of pediatric oncologists had ever met at PAHO Headquarters to discuss pediatric cancer, define the problems faced in the Region, and identify potential strategies for addressing them. Ms. Luciani also pointed out that despite improved treatments, there are still major disparities in pediatric cancer mortality in the United States and Canada as compared to LAC. Closing that gap is clearly the ultimate objective of this Pediatric Cancer Working Group, and the discussions revolved around this challenge.

SESSION 1: GLOBAL AND REGIONAL ANALYSIS OF PEDIATRIC CANCER

During the first session the work and objectives of the Lancet Oncology Commission on Sustainable Paediatric Cancer Care were presented, as well as preliminary results from a study the University of Chile is conducting to map pediatric cancer in the Americas, and to highlight successful models in the Region.

Lancet Oncology Commission on Sustainable Paediatric Cancer Care

Sumit Gupta, Oncologist, The Hospital for Sick Children (SickKids) Sumit Gupta of the Hospital for Sick Children (Toronto) presented the structure, duties, and work plan of the Lancet Oncology Commission on Sustainable Paediatric Cancer Care. The Commission seeks to create an investment environment that favors the treatment of pediatric cancer in low- and middle-income countries (LMIC), based on the model previously used to encourage investment in HIV/AIDS treatment. The group also seeks to establish a set of pediatric cancer goals to be reached by 2030. There are numerous participants on this Lancet Oncology Commission around the world and they are distributed in three working groups. Working Group 1 seeks to determine the current burden of disease for pediatric cancer in LMIC, as well as the projected burden for 2030 if no action is taken to reduce it. Working Group 2 assesses the number of services available for pediatric cancer and the levels of services that are available. Finally, Working Group 3 seeks to determine the cost of pediatric cancer treatment in LMIC—which is still unknown. The idea is to establish goals for 2030 and estimate the benefits (in terms of deaths avoided and economic benefits) that would be realized by achieving these goals. The group also estimates what the cost would be and what path should be followed to achieve these goals. At the time of the meeting, the three groups were compiling the required information, and had planned a meeting for September of 2017 in which they will proceed to establish the goals for 2030, which will later be shared with the World Health Organization (WHO) during the World Health Assembly of May 2018. Dr. Gupta concluded his presentation by pointing out the synergies between the Lancet Oncology Commission and the PAHO Working Group, including the willingness of both groups to complete an analysis of policies in order to raise awareness during the 2018 World Health Assembly.

Case Studies for Pediatric Cancer in Latin America

Cristóbal Cuadrado, Professor, University of Chile

Dr. Cristóbal Cuadrado presented the preliminary results of a study that the University of Chile is conducting on the development and implementation of pediatric cancer national strategies and plans. The study is based on the premise that in developed countries, 80% of pediatric cancer cases get cured, while in the LMIC countries, the cure rate ranges from 10-60%. The study's objectives include:

1. Mapping approaches to pediatric cancer in Latin America in terms of leadership, financing, and governance;
2. Showing successful models in the Region in which pediatric cancer is already adequately integrated into health systems; and
3. Obtaining a commitment from leading regional and global organizations to support the development of cancer registries, and to advocate for national pediatric cancer actions.

The study's methodology includes comparative case studies, and the distribution of surveys among representatives of ministries involved in addressing pediatric cancer, treatment centers, parents' organizations, and foundations in each country of Latin America. Dr. Cuadrado noted how hard it is to identify the people in charge of pediatric cancer at the ministries, since often there is no specific pediatric cancer department, or this activity is managed by different units. It is also difficult to locate the parents' groups, which are often only loosely organized. Despite these challenges, at the time of the meeting 17 ministerial representatives, as well as different treatment centers and parent groups, had been located and contacted.

The study has already compiled and analyzed half of the information. An overview was presented of the preliminary results, including information on various aspects of pediatric cancer, such as: funding, economic barriers, problems of access, referral networks, the existence of protocols and accreditation certificates at health centers, estimating survival rates and treatment dropout rates, access to essential drugs and other medications, human resources, and positive experiences in the Region.

Data collection for the study will be completed in 2017. Preliminary reports will be drafted to help describe various aspects of health system responses, including the challenges and experiences of managing childhood cancer in the Region. Dr. Cuadrado shared the good news that solutions have been put forth in the Region to address the problem of pediatric cancer. In order to fine tune the available information, it is important to achieve good communication with groups of parents that use these services.

Session 1 discussion

Different aspects of the Session 1 presentations were discussed. First, the representative of Costa Rica spoke about the challenge of handling migrant populations that often escape registry and suffer from high treatment dropout rates. Mention was made of the need in this context to draw a distinction between loss of treatment and monitoring, as well as the importance of capturing dropouts and identifying those who refuse treatment, because the latter are not even considered when discussing dropout rates.

Dr. Curt Bodkyn (Trinidad and Tobago) expressed an interest in replicating Dr. Cuadrado’s study, but adapting it to the Caribbean. He said this data must be collected because it can help governments to prioritize.

In response to the presentation by Dr. Sumit Gupta, Dr. Betzabé Butrón from PAHO called upon participants to vary the arguments presented to governments, and include not just economic analyses but also ethical arguments when advocating for efforts to combat childhood diseases. She also said it was essential to include children’s opinions in the information compiled, since they are the services’ users and can help a lot in their improvement. In response, Dr. Gupta agreed on the need for ethical arguments, but insisted that economic information must still be compiled. Dr. Cuadrado added that governments will always have to prioritize their activities. However, aside from economic arguments, it is important to ensure that governments’ decisions are informed by the available evidence. He also said that while it would be good to get input from children, this may be unfeasible because there are some ethical considerations which limit this possibility. Finally, Dr. Cuadrado said that much of the data in his presentation could be applied to any health issue and that regarding pediatric cancer, perhaps efforts should be joined with other child health programs to enhance the chances of success, since there are many commonalities to be explored in the search for solutions.

Another issue discussed was drug availability. Dr. Federico Antillón (Guatemala) described problems in procurement processes, particularly for unregistered drugs. Also, low demand causes prices to go up. Dr. Myriam Campbell pointed out that procuring drugs is a problem faced by single parent families when taking care of children with cancer.

SESSION 2: COUNTRY EXPERIENCES WITH PEDIATRIC CANCER CARE

Marcelo Scopinaro and Florencia Moreno (Argentina); Myriam Campbell (Chile); Federico Antillón (Guatemala); Armando Peña (Honduras); Cheryl Alexis (Barbados); Caridad Verdecia (Cuba); Jaime Shalkow (Mexico)

Prior to the meeting, the participants received a series of questions about childhood cancer in their countries that included: the epidemiological situation, policies and health systems, weaknesses and challenges for improving management, key players in pediatric cancer care, and the supports needed to establish a pediatric cancer program in their countries. In this session the representatives of Argentina, Chile, Guatemala, Honduras, Barbados, Cuba, and Mexico presented information from their respective countries.

Epidemiological situation of pediatric cancer

Figure 1 shows incidence and mortality rates for pediatric cancer in LAC based on Globocan 2012 data. Incidence and mortality rates reported by the countries at the meeting largely coincide with those shown in **Figure 1**. The exceptions were Barbados and Mexico, which reported incidence rates higher than those of Globocan. For Barbados, the discrepancy is possibly due to an increase in the number of cases diagnosed, thanks to the registry conducted from 2012-2016 through the Sick Kids-Caribbean Initiative (see presentation below).

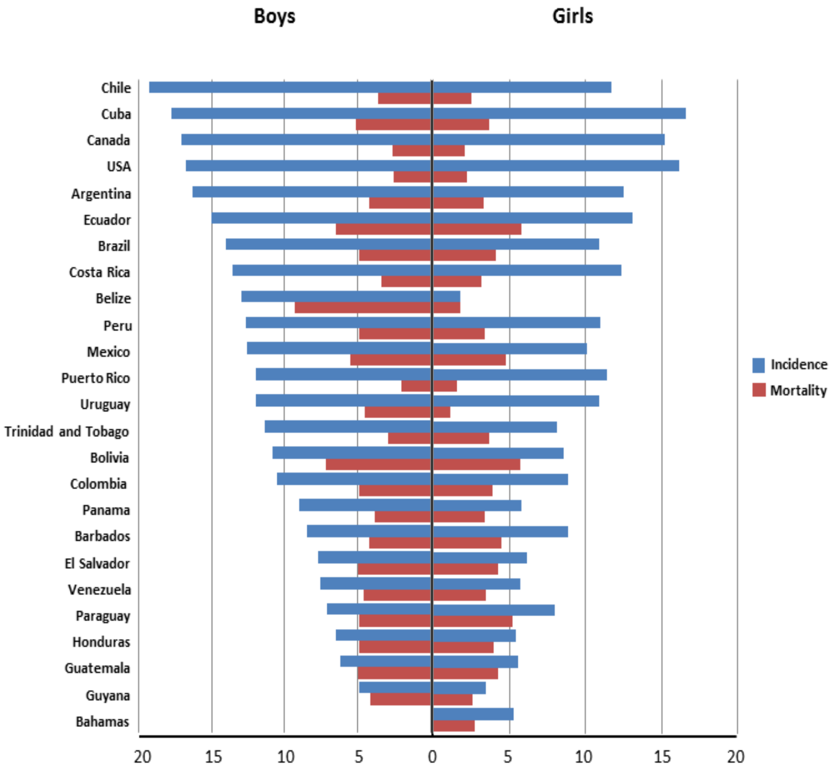

Figure 1. Estimate of incidence and mortality of cancer in children under 15 in LAC (**Source:** Globocan, 2012, http:/globocan.iarc.fr/Default.aspx).

The most common cancers in children are leukemia, which, to a greater or lesser extent, is predominant in all countries, followed by tumors of the central nervous system and lymphomas. All countries reported an increase in the five-year survival rate for pediatric cancer patients. Specifically the five-year survival rates reported by the representatives of the countries were 61% (Argentina), 79% (Chile), 67% (Guatemala), 61% (Honduras), 69% (Barbados), and 52% (Mexico). Cuba did not provide an overall survival estimate, but indicated that it varies from 20-50% for central nervous system tumors to 80-90% for Hodgkin's lymphoma. Some countries, such as Argentina and Mexico, reported significant differences in survival rates among their different regions. The general trend is that the likelihood of surviving pediatric cancer is greater in wealthier areas, which is consistent with the differences in diagnostic capacities between rural and urban areas reported by Guatemala. Finally, it should be noted that both Mexico and Honduras reported that a significant number of deaths among child cancer patients (which Mexico estimated at 13%) are caused by infections. This is most likely true in other countries of the Region as well.

As for cancer registries, some countries, such as Argentina, Chile, and Cuba, reported that they have rather complete hospital-based cancer registries. However, the representatives of Honduras (who questioned the reported survival rate) and Mexico reported that their databases were either out of date or incomplete, and should be improved. Mexico reported that, like Barbados, it was starting a Single Child and Adolescent Cancer Registry (RUCIA).

Health policies in pediatric cancer

Argentina, Chile, Honduras, Mexico, Barbados, and Cuba reported that they have public universal health systems in which pediatric cancer care is covered and free of charge for 100% of patients. This does not prevent a percentage of patients from seeking private health care, for example in Argentina and Chile (ISAPRES). In these countries pediatric cancer care is funded through the health budget paid by citizens' taxes. In Guatemala cancer care is provided through the National Pediatric Oncology Unit (UNOP) and is free for patients up to 18 years of age. UNOP is funded through the Ministry of Health, which contributes one third of the budget, and the "Ayúdame a Vivir" Foundation ("Help Me Live" – AYUVI), which uses contributions from St. Jude Children's Research Hospital and other international centers to fund the remaining two thirds.

In most LAC countries, pediatric cancer care is covered and free of charge for all patients. Nevertheless, participants described a serious problem of inequity in access to pediatric cancer diagnosis and treatment. This is primarily due to differences in the quality of care offered at different establishments. For example, in Guatemala it is estimated that only 47% of cases are covered, and most of the "missing cases" (defined as the difference between the expected number of cases and the number diagnosed) are in rural areas. Dr. Armando Peña from Honduras said that the San Pedro Sula area had half as many resources as those available in the capital city of Tegucigalpa, for a similar-sized population. Mexico also indicated that both the place of residence and the institution providing pediatric cancer care have a great influence on cancer outcomes. The small island countries of the Caribbean face special challenges in providing access to services for their residents. For them, transportation and lodging can be barriers to access.

Health systems and pediatric cancer care

The participants agreed that the quality of pediatric cancer services in their countries has room for improvement. Although there are examples of centers that render high quality service, many others lag far behind. A survey conducted in Mexico[1] showed that these differences in quality correlate with survival rates. Honduras pointed to the problem of frequent use of poor quality generic drugs. This indicates a need to set up an efficient procurement system and to encourage use of the PAHO Strategic Fund.[2] In addition, the cancer registries have a lack of quality.

The capacity of health systems to manage pediatric cancer is not uniform within countries. For example in Honduras, the San Pedro Sula area has half the resources that the capital, Tegucigalpa, has for a similar-sized population. Mexico reported a shortage of beds for adolescents with cancer and that no care is available on holidays. Several countries reported insufficient capacity for palliative care. Human resources are still being developed in Guatemala, Mexico, Honduras, and Barbados, which reported a need for training of primary and secondary care personnel. The Barbados participant indicated that the public sector in the country generally has gaps in diagnostic capacity, pathology and radiology services, referrals, and availability of drugs. The exceptions were Cuba—which reported high quality services distributed throughout the country and good cancer registries—and Chile, which thanks to the National Antineoplastic Pediatric Drug Program (PINDA) is leading the Region in terms of capacity.

Countries also reported that progress has been made to improve the health systems' management of pediatric cancer. Argentina has made significant investments in hospital infrastructure and human resources. In Chile, PINDA has contributed to human resources training, the creation of infrastructure, the incorporation of new technologies, and the continuous upgrading of equipment. In Guatemala, the establishment of UNOP increased the number of beds for both routine care and intensive care units (ICUs), a hospice for terminally ill children was established, and a second pediatric cancer clinic is being constructed. These investments have resulted in a general improvement of pediatric cancer diagnosis in the Region as well as in improved treatment capacity, better distribution of services, a reduction in treatment dropout rates, and increased survival rates.

Personnel training programs for the management of pediatric cancer

Some countries reported that they have pediatric cancer training programs. Argentina explained that its National Cancer Institute has fellowships in pediatrics, oncology nursing, and palliative care, while there are training programs at the Garrahan Pediatric Hospital, the University of Buenos Aires, and the Flexer Foundation (which works with families). The Argentine Pediatric

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[1] Esparza-Aguilar M, et al. Outcome disparities in 11,410 Mexican children with cancer: fundamental knowledge to direct public health policy. Pediatr Blood Cancer. 2015;62:S170.

[2] Enlace: http://www.paho.org/hq/index.php?option=com_content&view=article&id=12163%3Apaho-strategic-fund&catid=8775%3Aabout&Itemid=452&lang=es.

Society has a national program and provides its pediatricians with information on cancer. In Chile there are training programs at the country's main universities in pediatric oncology-hematology, in pediatric oncology nursing and nurse training, and in palliative care.

Guatemala has a graduate-level course in pediatric oncology, including training in pediatric intensive care and a degree course in palliative care, all financed by St. Jude Hospital and coordinated by UNOP and the Francisco Marroquín University. In Honduras there are nurse training programs, including a program that helps detect patients with serious infections. The limitation of these programs is that nurses do not have much ability to travel for training, especially when they have families. Barbados has no training programs of its own, and all staff being trained now—hematologists, pediatric oncologists, and nurses—receive their training overseas.

Strengths, weaknesses, opportunities, and threats for improving pediatric cancer care (SWOT analysis)

The participants were required to include a SWOT analysis in their respective presentations (strengths, weaknesses, opportunities, and threats) for the improvement of pediatric cancer programs. **Figure 2** gives a general summary of the points made by all countries. But in the SWOT analysis some specific issues stood out for each country, which we will summarize in the following paragraphs.

With regard to **strengths**, Argentina mentioned its hospital-based registry (Hospital Pediatric Oncology Registry – ROHA), its interdisciplinary management of pediatric cancer, and the establishment of new control, care, and monitoring centers. Chile pointed out that its childhood cancer program has a system for financial protection and guarantees. This country also has skilled personnel, a series of protocols, quality standards that are proven to be effective, and a good pediatric cancer registry. Guatemala and Honduras reported as a strength their collaboration with the Pediatric Hematology Oncology Association of Central America (AHOPCA), which is in charge of establishing partnerships with hospitals in high-income countries and providing financial support for various activities related to pediatric cancer. Honduras indicated that the EVATH nurse training program was one of its strengths, and Barbados cited the introduction of telemedicine for better pediatric cancer case management[3] as one of its strengths.

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[3] Adler E, et al. Bridging the distance in the Caribbean: telemedicine as a means to build capacity for care in pediatric cancer and blood disorders. Stud Health Technol Inform. 2015;209:1-8.

Strengths

- Examples of successful public-private initiatives and collaboration with external agencies (St. Jude Hospital, Hospital for Sick Children).
- Strong local leadership in some countries, such as Argentina (INC), Chile (PINDA), and Guatemala (UNOP).
- Complete cancer registries in Argentina, Chile, Cuba, and Barbados and plans to improve registries in Mexico and Honduras.
- Successful training programs with university endorsement.
- Research.

Weaknesses

- Shortages of specialists, overburdened health workers, uncompetitive wages, instability, and high turnover rates.
- Shortage of resources and inadequate regional coordination infrastructure that results in saturation of infrastructures.
- Lack of diagnostic capacity (pathology services).
- Problems with patient referral systems.
- Problems with access to high quality drugs (Barbados and Honduras).

Opportunities

- Improvement of diagnostic capacity programs and improved local and international fundraising.
- Strengthening of research and surveillance systems so that new interventions can be implemented.
- Education and mass communication to raise awareness about pediatric cancer.
- National and international strategic partnerships

Threats

- Competition with other health priorities and general lack of continuity in policies.
- Weak institutions and care networks.
- Trend toward privatization of medicine and migration of professionals to primary care.
- Increased costs of diagnostic and therapeutic methods.
- Lack of awareness among the population and decision-makers.

Figure 2. SWOT analysis on improving pediatric cancer program capacities in the countries (**Source:** Session 2 presentations).

The **weaknesses** among the countries of the Region are much more uniform, and are summarized in **Figure 2**. However, there were some specific weaknesses mentioned by Chile, such as the exclusion of adolescents over age 15 in pediatric cancer programs, the large number of protocols that have not yet been published, and problems with implementing new diagnostic techniques. Honduras and Barbados pointed out inadequate access to quality medications, and Honduras does not yet have a national pediatric cancer program.

As for **opportunities,** in Argentina this includes establishing better coordination between the National Cancer Institute of Argentina (INC), the Ministry of Health, and new local legislation. In Chile it is important to improve the existing program and take advantage of the knowledge gleaned from its successes to help institute new interventions and disseminate the results nationally and internationally. In Honduras and Barbados it is important to improve pediatric cancer facilities and services. And in Mexico it will be key to strengthen strategic partnerships, education, and mass communication.

Among the principal **threats** is the fact that pediatric cancer programs must compete with other health priorities, which may leave them inadequately funded. This threat increases with the growing complexity and cost of diagnostic and therapeutic methods for pediatric cancer. There may also be a lack of continuity in health policies when a new government comes into office. Chile identified as a threat the risk of health personnel moving to the private sector, the fragile nature of the care network's ability to maintain the quality of service, and problems with training specialists, a concern shared by Mexico.

Key players in pediatric cancer care in LAC countries

The presenters reported on an array of key actors involved in managing pediatric cancer in their countries, which is summarized in **Table 1.** In general, the actors at the national level include the Ministries of Health, hospitals, cancer institutes, scientific societies, and universities. In Argentina, mention was made of the Garrahan Hospital Network, which has 160 centers, and the INC. The country also receives international support from the Latin American Pediatric Oncology Group (GALOP). In Chile, the National Cancer Commission and its PINDA program follow PAHO/WHO recommendations to facilitate access to pediatric cancer diagnosis and treatment. PINDA receives support from several international partners, such as St. Jude Hospital (which shares knowledge and experience to improve diagnosis and treatment), Vall d'Hebron Institute of Oncology (VHIO), and the Hospital for Sick Children (in charge of training specialists). In Guatemala the AYUVI Foundation and UNOP are the main national partners, but the country also receives outside support from St. Jude Hospital and the Pediatric Hematology Oncology Association of Central America (AHOPCA), the Monza International School of Pediatric Hematology/Oncology (MISPHO), Boston Children's/Dana-Farber, and My Child Matters. Honduras also receives international support from St. Jude Hospital and AHOPCA. Barbados has been receiving support from the SickKids-Caribbean Initiative (SCI) to develop cancer registries. In Mexico, the local actors are the National Board for the Prevention and Treatment of Child and Adolescent Cancer (CONACIA) and the Specific Program of Action for Pediatric Cancer (PAE).

Table 1. National and international partners for pediatric cancer care in Argentina, Chile, Guatemala, Honduras, Barbados, Cuba, and Mexico (as reported by speakers).

Country	Key Actors	
Argentina	**National**	• National Cancer Institute (INC)-MOH • Garrahan Hospital Network • Argentine Society of Pediatric Hematology/Oncology (SAHOP) • Argentine Group for Acute Leukemia Treatment (GATLA) • Flexer Foundation and Associates
	International	• Latin American Pediatric Oncology Group (GALOP)
Chile	**National**	• National Cancer Commission • National Antineoplastic Pediatric Drug Program (PINDA)
	International	• BFM International Study Group • St. Jude and Vall d'Hebron Hospitals and Hospital for Sick Children
Guatemala	**National**	• Cancer survivors and the communities • "Ayúdame a Vivir" Foundation (AYUVI), National Pediatric Oncology Unit (UNOP) • Francisco Marroquín University
	International	• St. Jude Hospital • Pediatric Hematology Oncology Association of Central America (AHOPCA) • Monza International School of Pediatric Hematology/Oncology (MISPHO) • My Child Matters • Boston Children's/Dana-Farber
Honduras	**National**	• Multidisciplinary group • The state • Community • University
	International	• St. Jude Hospital • AHOPCA
Barbados	**National**	• Ministry of Health • Charitable organizations
	International	• SickKids-Caribbean Initiative (SCI)
Cuba	**National**	• Government and Ministry of Health
	International	• None mentioned
Mexico	**National**	• National Board for the Prevention and Treatment of Child and Adolescent Cancer (CONACIA) • Specific Program of Action for Pediatric Cancer (PAE)
	International	• None mentioned

Support required to establish or improve pediatric cancer programs

The country representatives indicated what support was needed to improve their pediatric cancer programs. These needs are generally related to funding or training of personnel, but some unique needs were mentioned for certain countries. Argentina indicated a need to establish a national data center, increase human resources, improve program monitoring, and create a passport for survivors. Chile pointed to the need for training and continuing professional education for its professionals. This country also needs support to create a pediatric biobank, conduct collaborative research studies, establish a bone marrow donor registry, and create a child cancer registry. Guatemala said that it needs to increase its financial resources. Honduras particularly wants support from international organizations to ensure access to oncology drugs at affordable prices, and to create a palliative care unit. Barbados also requested support for the procurement of drugs as well as regional advocacy.

SickKids-Caribbean Initiative: significant aspects of Phase I and plans for Phase II

Corrine Sinquee-Brown, Ministry of Health, Bahamas

The SickKids-Caribbean Initiative (SCI) is a good example of international collaboration to establish pediatric cancer programs. Dr. Sinquee-Brown presented the most significant aspects of this collaboration between the SickKids Centre for Global Health and the University of the West Indies in which six countries participate: Bahamas, Barbados, Jamaica, Saint Lucia, Saint Vincent and the Grenadines, and Trinidad and Tobago. SCI tries to improve the prognosis of children with cancer or blood disease in the Caribbean. To this end, it promotes the use of data on best practices in patient management and also for evidence-based decision-making. In addition, SCI works to increase the availability of and access to diagnostic services and greater academic visibility through research and publications. SCI helps train people in primary care, helping them to improve management of patients with cancer and blood disease. It also works to develop databases and establish channels of communication among the different local actors.

Thanks to SCI, some guidance documents adapted to the Caribbean have been prepared, hundreds of health workers have been trained, and numerous diagnostic tests and medical visits have been conducted, resulting in a database of more than 400 patients. During **Phase I**, SCI has established partnerships with Ministries of Health, hospitals, and other stakeholders; a regional team-based approach has been used; and data management has been strengthened. The challenges this initiative faces are: implementing a monitoring and evaluation plan, extending funding, establishing responsibilities, selecting the appropriate indicators, and developing a sustainability plan. Dr. Sinquee-Brown explained the activities to be carried out in **Phase II**, including more use of telemedicine, transferring responsibilities to the Caribbean teams, investing in the capacity to develop databases, creating academic degree programs, and launching advocacy groups. Dr. Sinquee-Brown shared the thought that countries with such small populations as those of the Caribbean islands need to band together so they can be heard in international forums, and should join efforts in the areas of research, staff training, drug procurement, and setting standards for best practices. In conclusion, SCI has established partnerships with prestigious international organizations, has leveraged fundraising, and the six countries participating in the Initiative have clearly benefited from it. It will be important for this organization to remain active in the near future.

Session 2 discussion

A key observation after the session on country experiences was that countries faced many of the same challenges and opportunities. For this reason, Dr. Sumit Gupta pointed out the need for joint advocacy to address these challenges.

Questions were also asked about the situation of undocumented immigrants. The representatives of Chile and Costa Rica stated that all children receive care in the public health system and that there is a legal obligation to provide this care. In Costa Rica, if the child's family has the means to do so, they generally pay for services. Chile was asked whether survival rates were the same for patients at private and public health facilities. According to Dr. Myriam Campbell, the data included in the cancer registry show that survival rates are similar in both public and private clinics and both private and public clinics use the PINDA protocols.

SESSION 3: IDENTIFYING IMPROVEMENTS NEEDED IN PEDIATRIC CANCER CARE

After the first two sessions, the Working Group made an effort to identify the priority requirements to improve the situation of pediatric cancer in LAC.

Outcome of the UICC/SickKids/Brocher meeting

Avram Denburg, Pediatric Oncologist, Hospital for Sick Children

Dr. Avram Denburg presented a summary of the meeting held in 2015 between the Brocher Foundation, the UICC, and Hospital for Sick Children (SickKids). In that meeting there was a discussion about coordinating the various stakeholders for developing pediatric cancer programs in Latin America. There was an effort to link evidence with policymaking. Another objective of the discussion was to empower the different stakeholders to make effective changes in policy.

The group identified several problems related to pediatric cancer in the Americas. First, although the burden of pediatric cancer is considerable, it is measured inconsistently. Second, there are regional differences in access, which result in differences in prognosis. Third, systems need to have better coordination between practices and policies. And finally, politicians are not paying enough attention.

The group came up with three possible solutions to address these issues. First, they suggested that a Region-wide working group be created to clearly identify the challenges and their potential solutions, to afford opportunities for supranational collaboration, and to establish priorities and plans of action. Second, guidelines should be established for health systems, with knowledge centers and opportunities for stakeholders to participate in policymaking. Third, a good monitoring and evaluation system should be implemented, including high quality cancer registries and indicators through which all the countries could be evaluated and compared.

At the 2015 meeting examples of solutions that could be applied to the different problems were discussed. For example, for the problem of procurement and access to drugs, the **Regional Working Group** could offer a regional approach to negotiate prices and procure and distribute drugs. Next, the **health systems guidelines** would help institute processes similar to those of PAHO for national drug procurement and distribution. Finally, **monitoring and evaluation** would help strengthen the cancer registries. Examples of solutions to this problem would include the WHO List of Essential Medicines and PAHO's Strategic Fund.

Several activities were deemed to be priorities, such as advocacy, generating data and evidence, stakeholder involvement, and creating the Regional group. The latter was to have the following characteristics: a clear purpose, well-defined foundational values, strong governance, and a focus on Region-wide activities. The Regional Working Group would include different elements and activities to ensure that all participants are moving in the same direction toward development of pediatric cancer programs. Dr. Denburg laid out the next steps for this PAHO working group: identify barriers, challenges, and needs for improving pediatric cancer programs.

Moderated discussion to identify barriers, challenges, and needs to improve pediatric cancer outcomes

Tom Gross, Deputy Director of Science, National Cancer Institute, U.S.

Once the situation of pediatric cancer programs in LAC was described, Dr. Tom Gross of NCI moderated a discussion on possible strategies to follow to overcome the current weaknesses in pediatric cancer management. During this discussion, the countries that did not have the opportunity to make presentations during Session 2 were able to share the shortcomings of their health systems regarding pediatric cancer care. One challenge almost all countries shared was limited resources and the lackluster quality of their cancer registries.

Tom Gross emphasized that in LAC, health systems are at different levels in terms of their capacities to improve pediatric cancer outcomes. Chile was particularly mentioned as a good example for the Region, since it has developed a robust program with very little foreign help. It was deemed very important for each country to identify its own challenges and needs, since the models used in one country can rarely be directly applied to another.

Dr. Federico Antillón of Guatemala pointed out that in his country the priorities are to improve drug procurement mechanisms, and to improve cancer registries and early diagnosis. The situation is similar in Colombia and Argentina, which expressed an interest in learning about the drug procurement mechanisms of other countries. Dr. Roberto Vásquez (El Salvador) opined that his country's Ministry of Health has problems ensuring the quality of health services. Thus, in order to improve pediatric cancer early diagnosis services, general pediatric services must first improve. For example, in El Salvador the pediatric data collection systems are quite limited.

Dr. Curt Bodkyn (Trinidad and Tobago) pointed out that a big problem for the Caribbean countries is the lack of lodging for patients and their families that have to go to other islands to receive pediatric cancer treatment. Another problem that several of the participating countries agreed on was the quality of generic drugs, and the need for a list of trustworthy sources from which to purchase them. The countries also identified a lack of drugs to treat infections, which, as was indicated during the Session 2 presentations, constitute a major cause of mortality for pediatric cancer patients. To this, Silvana Luciani replied that the PAHO Strategic Fund is a good tool for guaranteeing drug quality; however few countries are using it to purchase cancer drugs. For this reason, she said that one of the meeting's recommendations should be for countries to make better use of the Strategic Fund.

Day 2. Content and Summary of Presentations

SUMMARY OF DAY 1 DISCUSSIONS

A brief review of the first day's conclusions was provided, in which the countries reported on their epidemiological situations and the capacity of their health systems to address pediatric cancer. **Figure 2** provides a summary of the information countries shared on Day 1 regarding their strengths, weaknesses, opportunities, and threats (SWOT analysis). After discussing this information on the first day of the meeting, the Working Group spent the second day discussing possible strategies to improve pediatric cancer care and what actions should be taken by the Working Group.

SESSION 4: STRATEGIES TO IMPROVE PEDIATRIC CANCER CARE IN LAC

Once the needs of the countries were identified, the group began to discuss strategies to improve pediatric cancer programs in LAC. To open the discussion, Armando Peña (Honduras) and Marcelo Scopinaro (Argentina) said that the most important thing when striving to develop pediatric cancer programs is to be able to work well with the Ministries of Health. To this end, the Working Group must stay in close contact and understand that one of its objectives is to put forth solutions and reach specific agreements. Avram Denburg supported the idea of fostering that communication. In order to develop effective strategies, it will be essential to share information among countries and identify two or three issues that can only be solved by working together. Avram Denburg specifically proposed the joint purchase of drugs and joint advocacy.

Amaranto Suárez (Colombia) agreed with the idea of making a commitment to issue recommendations to help procure essential medicines, and getting governments to commit to ensuring continuity of treatment. He also talked about addressing educational/pedagogical issues, and reducing patient referral times (perhaps through a system of incentives and disincentives—expedited pathways). A final important topic is that of developing good pediatric cancer mortality registries, because there may be different determinants.

AGREEMENTS, NEXT STEPS, AND FINAL CONSIDERATIONS

At the conclusion of the meeting, the Working Group identified a series of steps to improve pediatric cancer programs in Latin America and the Caribbean. They were divided into short-, medium-, and long-term actions.

Short-term actions included:

1. Formalize the Pediatric Cancer Working Group coordinated by PAHO, with a well-established mission, purpose, and governance.
2. Prepare a report on the meeting to serve as an advocacy and awareness document to be used with the Ministries of Health and other interested parties.
3. Widely disseminate the presentations, the report, and the recommendations of the meeting through the websites of PAHO, UICC, St. Jude Hospital, and the Hospital for Sick Children.
4. Develop and disseminate health care guidelines for children with cancer. These should include psychosocial support, standardized protocols, skilled personnel, good quality drugs, and timely response. The guidelines could be adapted from those of UICC or the International Society of Paediatric Oncology (SIOP).
5. Share with the Working Group the list of drugs for pediatric cancer and palliative care included in the PAHO Strategic Fund, in addition to the contacts and procedures required for using the fund.
6. Develop advocacy for use of the PAHO Strategic Fund to purchase pediatric cancer drugs.

Medium- and long-term actions included:

1. Conclude the analysis and mapping of pediatric cancer in Latin America and start this analysis in the Caribbean countries.
2. Organize national meetings and multidisciplinary discussions in the countries of the Region in order to develop local strategies to improve policies, health systems, and services for children with cancer.
3. Produce a factsheet on pediatric cancer indicators in the Region, using data from the International Agency for Research on Cancer (IARC).
4. Establish cancer registries and data and monitoring training programs.
5. Analyze cost savings associated with use of the Strategic Fund in certain countries, with a view to conducting advocacy.
6. Develop early detection strategies, applying the PAHO manual on diagnosing cancer in children.

7. Work with Childhood Cancer International (CCI) and the “Nuestros Hijos” Foundation (“Our Children”) to conduct advocacy and provide guidelines, recommendations, and training to improve palliative care services for children with cancer.
8. Support the development of evidence-based clinical protocols and promote their use, in addition to disseminating existing protocols, with the support of St. Jude, the Hospital for Sick Children (SickKids), AHOPCA, and Physician Data Query (PDQ) of the United States’ National Cancer Institute.

APPENDIX 1: Program

Thursday, 2 February 2017

8:30 a.m.	**Registration of participants**
9:00 a.m.	**Welcome and Review of the Meeting Objectives** *Silvana Luciani*, Advisor in Cancer Prevention and Control, PAHO
9:15 a.m.	**SESSION 1: GLOBAL AND REGIONAL ANALYSIS OF PEDIATRIC CANCER** *Moderator: Silvana Luciani* Lancet Oncology Commission on Pediatric Cancer Dr. *Sumit Gupta*, Hospital for Sick Kids Questions and answers Latin America Case Studies on Pediatric Cancer *Dr. Cristóbal Cuadrado*,University of Chile Questions and answers
10:30 a.m.	**Coffee break** [key informant interview with one country during break]
11:00 a.m.	**SESSION 2: COUNTRY EXPERIENCES WITH PEDIATRIC CANCER CARE***: Dr. Monika Metzger* Country case presentations on pediatric cancer care organization, outcomes, and health system challenges to reduce mortality. Argentina: Dr. Florencia Moreno Chile: Dr. Myriam Campbell Bull Guatemala: Dr. Federico Antillón Honduras: Dr. Armando Peña Discussion, questions, and answers
12:30 p.m.	**LUNCH** [Project Team Meeting over lunch]
1.30 p.m.	**SESSION 2 cont'd: COUNTRY EXPERIENCES WITH PEDIATRIC CANCER CARE***: Dr. Tezer Kutluk* Country case presentation on pediatric cancer care organization, outcomes, and health systems challenges to reduce mortality. Barbados: Dr. Cheryl Alexis Cuba: Dr. Caridad Verdecia México: Dr. Jaime Shalkow

	Discussion, questions, and answers SickKids Caribbean Initiative: Highlights of Phase I and plans for Phase II Dr. Sumit Gupta, Hospital for Sick Kids Questions and answers
3:30 p.m.	**Coffee break** [key informant interview with one country during break]
4:00 p.m.	**SESSION 3: IDENTIFYING IMPROVEMENTS NEEDED IN PEDIATRIC CANCER CARE** *Moderator: Dr.* Tom Gross Outcomes of the UICC/Sick Kids/Brocher meeting *Dr. Avram Denburg*, Hospital for Sick Kids Moderated discussion to identify the barriers, challenges, and needs for improvement of pediatric cancer outcomes, based on the following questions: • What are the main gaps in health policies and services to improve outcomes for childhood cancer in your country? • What are the factors that are inhibiting improvements in health policies and services to fill these gaps in care? • What opportunities exist to improve childhood cancer in your country?
4:55 p.m.	**CONCLUSIONS**
5.00 p.m.	**ADJOURN for the day**

Friday, 3 February 2017

9:00 a.m.	**Review and highlights of previous day's discussion**
9:15 a.m.	**SESSION 4: STRATEGIES TO IMPROVE PEDIATRIC CANCER CARE IN LAC** *Moderator:* Dr. Sumit Gupta Moderated discussion to identify strategies and a plan to improve pediatric cancer care in LAC, based on the previous discussion on barriers and needs and covering the following topics: - Governance and financing of pediatric cancer care - Access to essential medicines, and clinical trials - Clinical protocols - Health human resources training

	- Monitoring and evaluation of outcomes (pediatric cancer registries).
10:30 a.m.	**Coffee break** [key informant interview with one country during break]
10.45 a.m.	**SESSION 5: INTERNATIONAL COLLABORATION AND TECHNICAL SUPPORT** *Moderator: Dr. Betzabé Butrón Riveros* Discussion on technical support available from PAHO, UICC, Sick Kids Hospital, St Jude's Hospital, and U.S. National Cancer Institute to support strengthening pediatric cancer care in LAC , as well as opportunities for South-South collaboration.
11:30 p.m.	**AGREEMENTS, NEXT STEPS, AND CONCLUDING REMARKS** *Moderator: Silvana Luciani* Agreement on the Working Group's tasks and next steps to finalize the regional analysis, and to develop the plan to improve pediatric cancer care in LAC.
12:30 p.m.	**LUNCH** [key informant interview with one country during break]
1:30 p.m.	**Concurrent sessions:** 1. Facebook Live activity to commemorate World Cancer Day 2. Finalize key informant interviews for the Latin America case studies with those who have not yet been interviewed. 3. Video recordings with experts for PAHO's media campaign. 4. Project team meeting.
4.00 p.m.	**ADJOURN**

APPENDIX 2: List of participants

Country	Name	Affiliation
Argentina	Florencia Moreno	National Cancer Institute
Argentina	Marcelo Scopinaro	Ministry of Health
Bahamas	Corrine Sinquee-Brown	Ministry of Health
Barbados	Cheryl Alexis	Ministry of Health
Brazil	Sandro J Martins	Ministry of Health
Chile	Myriam Campbell Bull	Ministry of Health
Chile	Cristóbal Cuadrado	University of Chile
Colombia	Anyul Milena Vera	Ministry of Health
Colombia	Amaranto Suárez	National Oncology Institute
Costa Rica	José Carlos Barrantes Zamora	National Children's Hospital
Cuba	Caridad Verdecia	William Soler Pediatric Hospital
Ecuador	Jessyca Karina Manner Marcillo	Francisco Icaza Bustamante Children's Hospital
El Salvador	Roberto Franklin Vásquez	Benjamin Bloom National Hospital
Guatemala	Federico G. Antillón Klussmann	National Pediatric Oncology Unit
Guyana	Latoya Gooding	Georgetown Public Hospital Corporation
Honduras	Armando Peña	University Teaching Hospital
Jamaica	Michelle-Ann Richards-Dawson	Bustamante Hospital for Children
Mexico	Jaime Shalkow Klincovstein	(CENSIA) Ministry of Health
Panama	Karina Quintero Delgado	Children's Hospital
Paraguay	Jabili Noguera	MSPBS Acusta Ñu Pediatric Hospital
Peru	Lourdes Ortega Vera	Ministry of Health
Peru	Sergio Antonio Murillo	National Institute of Child Health
Peru	Juan Luis García	National Institute of Neoplastic Diseases
Trinidad and Tobago	Curt Bodkyn	University of the West Indies
Uruguay	Gustavo Dufort y Alvarez	Ministry of Health
Hospital for Sick Children (Sickkids)	Avram Denburg Sumit Gupta	
St. Jude Children's Research Hospital	Monica Metzger	
UICC	Tezer Kutluk	
NCI	Tom Gross	
PAHO	Silvana Luciani	
PAHO	Betzabé Butrón Riveros	
PAHO	Bernardo Nuche-Berenguer	