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**Special report**

# Collaboration for success: the Global Initiative for Childhood Cancer in Latin America

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**ABSTRACT** The Global Initiative for Childhood Cancer (GICC) aims to increase the cure rate for children with cancer globally by improving healthcare access and quality. The Pan American Health Organization (PAHO), St. Jude Children's Research Hospital (St. Jude), and collaborators have joined efforts to improve outcomes of children with cancer in Latin America and the Caribbean (LAC) using the Cure*All* framework. In this article, we describe the process of developing regional resources aimed at accelerating the GICC implementation in LAC.

In March 2021, PAHO formed regional working groups to develop core projects aligned with Cure*All* pillars and enablers. Seven working groups emerged from regional dialogues: early detection, nursing, psychosocial, nutrition, supportive care, treatment abandonment, and palliative care. PAHO arranged regular online meetings under the mentorship and support of St. Jude regional/transversal programs and international mentors.

Between April and December 2021, 202 multidisciplinary experts attended 43 online meetings to promote the dialogue between stakeholders to improve childhood cancer outcomes. Fourteen technical outputs were produced: four regional snapshots, four technical documents, two virtual courses, one set of epidemiological country profiles, one educational content series for parents/caregivers, and two communication campaigns.

The ongoing dialogue and commitment of PAHO, St. Jude, LAC working committees, and international collaborators are essential foundations to successfully accelerate GICC implementation. This is achievable through the development of materials of regional and global relevance. Further research and evaluation are needed to determine the impact of these strategies and resources on childhood cancer outcomes in LAC and other regions.

**Keywords** Neoplasms; child health; intersectoral collaboration; health programs and plans; Latin America; Caribbean region.

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In Latin America and the Caribbean (LAC), more than 29 000 children and adolescents below the age of 19 are affected by cancer each year, and around 10 000 deaths are attributable to this condition (1). While childhood cancer survival has improved in the United States of America and other high-income countries to approximately 85% in recent decades (2, 3), substantial disparities among LAC countries are evident and growing (4, 5). Avoidable deaths from childhood cancers in low- and middle-income countries (LMIC) result from delayed diagnosis, misdiagnosis, treatment abandonment, malnourishment, toxicity-related fatalities, and inadequate access to effective treatments (6–8).

In 2018, the World Health Organization (WHO) launched the Global Initiative for Childhood Cancer (GICC) to increase the cure rate for children with cancer by improving healthcare access and quality. The GICC aims to reach at least a 60% global survival rate for children with cancer by 2030, by bringing together stakeholders across sectors toward a common goal using the Cure*All* framework in a coordinated operational approach (9).

The Pan American Health Organization (PAHO), in partnership with St. Jude Children's Research Hospital (St. Jude) and other partners, is collaborating to improve the prognosis of children with cancer in LAC (10). To accelerate the implementation of the GICC throughout LAC countries, PAHO is developing regional dialogues and resources addressing the leading causes of inadequate care, treatment failure, and death related to childhood cancer. In LMIC, where the burden of the disease is high (representing 80% of all childhood and adolescent cancer globally) (5, 9), resources for childhood cancer are particularly scarce, and the need for a culturally and regionally sensitive approach in the local language is even greater. In this article, we outline the development, validation, and dissemination of these regional resources, aligned with the Cure*All* framework of the GICC.

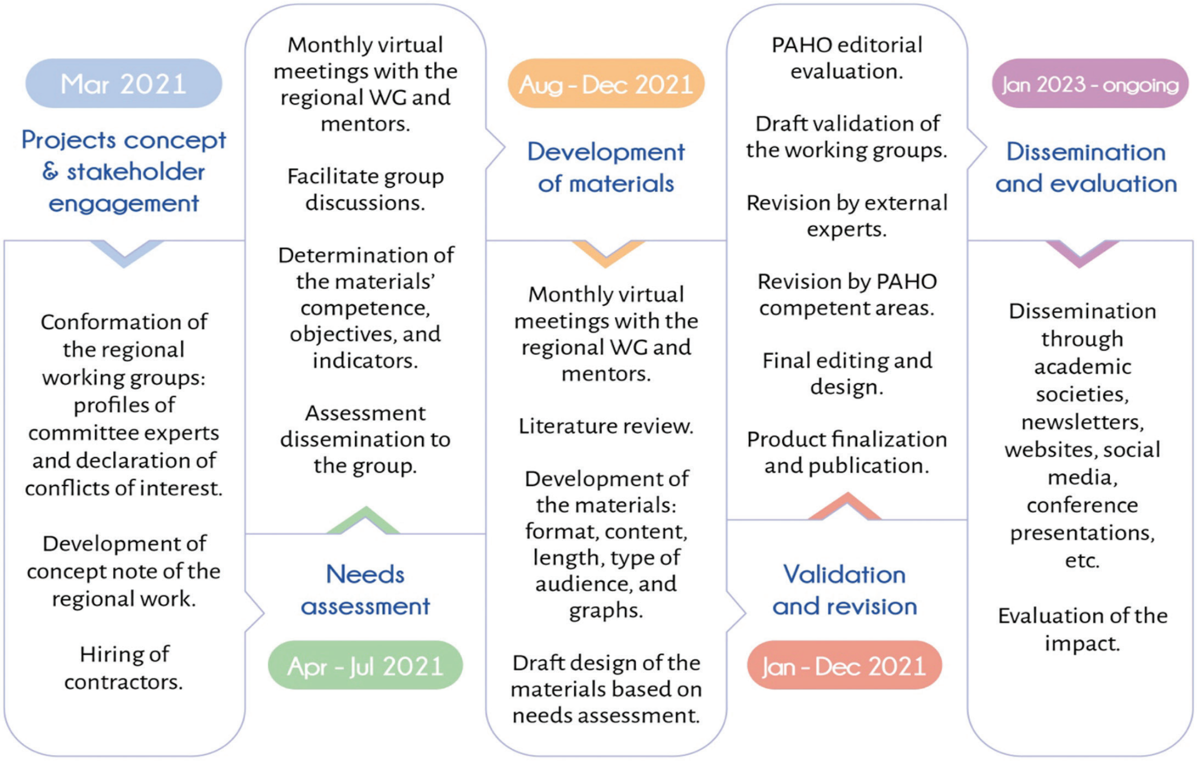
## MATERIALS AND METHODS

With the support of multidisciplinary expert working groups comprised of experts from LAC and international advisors, a multi-state approach was used to develop context-appropriate and patient-centered resources on childhood cancer in LAC. The initial approach was made based on methodological principles in five phases (Figure 1).

### Project concept and stakeholder engagement

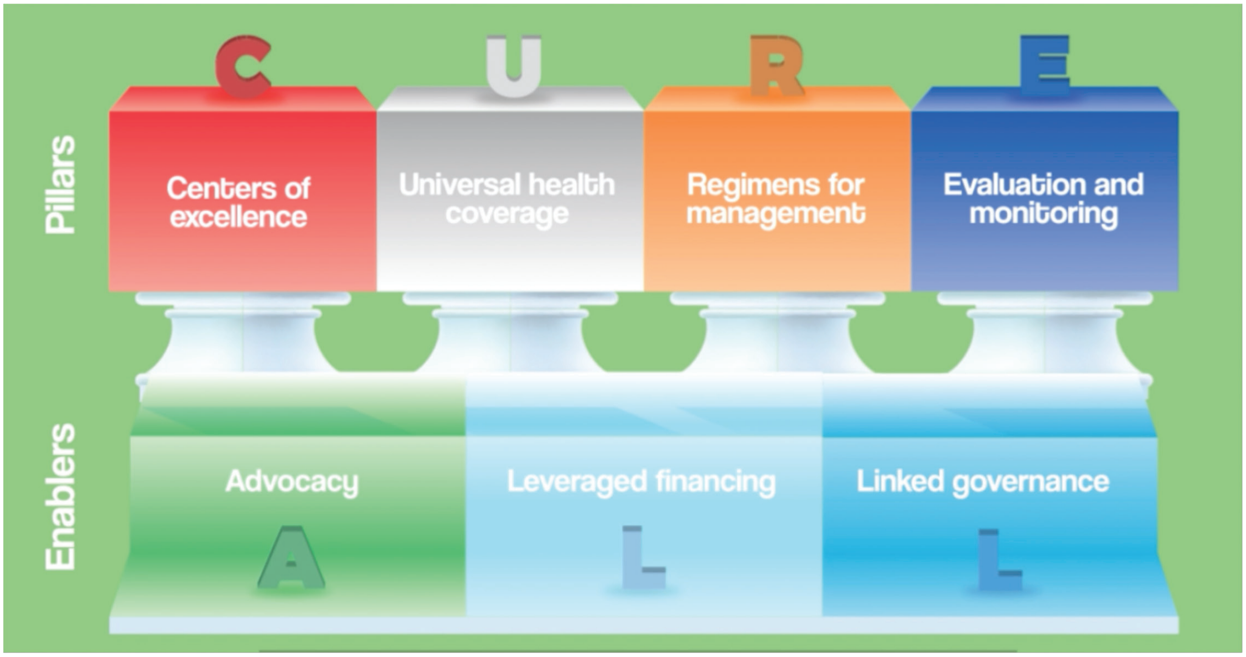
In March 2021, PAHO formed seven regional working groups (early detection, treatment abandonment, nursing, palliative care, nutrition, psychosocial, and supportive care) based on the main factors contributing to childhood cancer treatment failure, suboptimal care, and poor outcomes in LMICs, which include delayed presentation, misdiagnosis, abandonment of treatment, malnutrition, lack of supportive and palliative care, and limited access to curative therapies (6, 7, 11), and aligned them with the Cure*All* pillars and enablers (9) (Figure 2). PAHO

**FIGURE 1. Timeline of the components and activities used to develop the PAHO regional projects and interventions**



***Note:*** WG, working group.
***Source:*** Prepared by the authors.

**FIGURE 2. Cure*All* framework**



***Source:*** Adapted from: World Health Organization. Cure*All* framework: WHO Global Initiative for Childhood Cancer. Increasing access, advancing quality, saving lives. Geneva: WHO; 2021.

arranged regular online meetings with the support of St. Jude Global regional and transversal programs, along with international advisors. A concept note was developed outlining the main objectives and activities of the regional work, and five contractors were hired to provide expert technical assistance in specific topics (nutrition, nursing, oral care, psychosocial, and early diagnosis).

Under the coordination of the team from the PAHO Department of Noncommunicable Diseases, the participants of the working groups were convened through national and regional academic societies and partners in LAC. In all, 202 professionals from 21 LAC countries (Argentina, Bolivia [Plurinational State of], Brazil, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, El Salvador, Guatemala, Haiti, Honduras, Jamaica, Mexico, Nicaragua, Panama, Paraguay, Peru, Trinidad and Tobago, Uruguay, and Venezuela [Bolivarian Republic of]) working in pediatric oncology (pediatric oncologists, nurses, nutritionists, psychologists, social workers, among others) agreed to be part of the working groups to provide their expertise in the development and review of regional materials and resources on childhood cancer. For each interested professional, their resume was reviewed and the declaration of conflict of interest was requested. At least two international advisors were appointed for each of the working groups. They participated in the meetings upon request, and reviewed and monitored the proposals presented.

## Needs assessment

The participants of each working group conducted a needs assessment, based on dialogue and consensus. Monthly virtual meetings (90 to 120 minutes each) were established until a consensus was reached and consolidated into a proposal based on potential effectiveness, feasibility, and expected acceptability. During the needs assessment phase, the working groups discussed: 1) the work priorities (in response to the question: What main work priorities are necessary for this topic?) and 2) the opportunities for improvement (in response to the question: How are we going to achieve these work priorities?) (Table 1). The proposals for the resources to be developed were discussed step by step including the materials' objectives, target audience, content, and indicators of success. A form of communication was established with all the participants involved in the working groups by email, with consistent sharing of each of the meetings' minutes, agreements, and video recordings.

## Development of materials

Regular monthly virtual meetings with the regional working groups were maintained until December 2021 to perform a literature review for each of the materials to be developed. The working groups created a Google Drive cloud folder to collect local resources relevant to each topic, and every participant of each committee had permission to include materials in Spanish, Portuguese, or English. The PAHO cancer team assigned tasks for the members of the committees according to their level of expertise and interest. The proposed materials' format, content, and target audience were defined during the sessions. A final proposal for each material was presented to the committee for feedback and comments.

## Validation and revision

Between January and December 2022, the working groups were reached by email to receive remote access to the draft materials and resources, with permission for editing and commenting. Once the consensus for the final version was established by the committee and the PAHO cancer team, a

**TABLE 1. Overview of the work priorities and opportunities for improving pediatric cancer care, according to the PAHO regional working group needs assessment**

| | Priorities (What is needed?) | Opportunities (How to achieve it?) |
|---|---|---|
| **Early diagnosis** | • Training of health professionals (with a special focus on providers working in the primary level of care) in the timely detection of symptoms and signs of cancer in children and adolescents.<br>• Establishment and strengthening of national referral systems for pediatric patients with suspected cancer.<br>• Increasing community awareness about the symptoms and signs of cancer in children and adolescents.<br>• Development of telemedicine strategies for the timely diagnosis of childhood cancer.<br>• Inclusion of childhood cancer content in the undergraduate and postgraduate university program of health professionals. | • By increasing the availability and dissemination of educational resources (guidelines, reports, and courses) on early diagnosis of childhood cancer for healthcare providers, especially at the primary care level.<br>• By promoting joint efforts between different governmental and nongovernmental stakeholders in early detection programs (including operational work in pediatric cancer).<br>• By developing national and regional collaboration strategies for the development of projects for the timely diagnosis of childhood cancer.<br>• By creating or adapting massive communication strategies for the community (especially families and educators) in the early recognition of childhood cancer, in local languages. |
| **Palliative care** | • Early integration of palliative care into the cancer care of children and adolescents with cancer.<br>• Development of national and institutional regulatory standards on palliative care, including the standardization of quality indicators for palliative care.<br>• Training of health professionals at all levels of care about palliative care, as well as parents and caregivers of children with cancer.<br>• Equitable access to essential medicines for pain and management of symptoms; and quality home care. | • By increasing the availability and dissemination of educational resources (guidelines, reports, and courses) on pediatric palliative care (basic/advanced level) for healthcare providers.<br>• By developing technical guidelines and providing assistance aimed at the formation and strengthening of palliative care teams.<br>• By promoting articulated and collaborative work with palliative care leaders in the region and key organizations, at a national and regional level.<br>• By advocating with governments and institutions to ensure coverage of care, provision of medicines, and regulatory frameworks. |
| **Abandonment of treatment** | • Standard reporting systems for abandonment of childhood cancer treatment in Latin American and Caribbean (LAC) countries.<br>• Integration of multidisciplinary teams to prevent and control abandonment of treatment, including medical, psychological, social service, nursing, and volunteering teams.<br>• Articulated efforts and activities with nonprofit organizations and civil society, at a national and regional level.<br>• National legislations including financial support to families in vulnerable conditions and guaranteeing the rights of the child.<br>• Adequate information on treatment adherence for families of children with cancer through communication strategies adapted to the local reality with their own cultural and anthropological characteristics. | • By spotlighting the abandonment of childhood cancer treatment as a relevant issue to improve the care of children with cancer.<br>• By sharing success stories and improvement of the centers and countries in relation to the control of the abandonment of treatment for childhood cancer.<br>• By ensuring collaboration at a national and regional level to promote legislations, adequate country reporting, and cancer control strategies to improve abandonment rates.<br>• By advocating with governments to include activities for the prevention and control of treatment abandonment in national regulations. |
| **Nutrition** | • National and regional frameworks for standardizing early and quality nutritional assessment and care for children and adolescents with cancer.<br>• Better access to and coverage of nutritional support elements, as an essential part of pediatric cancer treatment.<br>• Research strategies on nutritional care in pediatric cancer in LAC countries.<br>• Educational projects and interventions for improving the nutritional care of pediatric cancer patients and their families. | • By promoting national and regional collaborative strategies on nutrition in pediatric cancer units in LAC countries.<br>• By the development of a regional guide for nutritional care in pediatric cancer patients, within the framework of the Global Initiative for Childhood Cancer (GICC).<br>• By advocating with governments to highlight the importance of delivering nutritional care during and after cancer in children and adolescents.<br>• By promoting informative materials aimed at professionals and families developed for the LAC region. |
| **Psychosocial** | • Better access to a quality psychosocial care for pediatric cancer patients and their families.<br>• Training of health professionals (including pediatric oncologists, nurses, psychologists, social assistants, and all professionals that are part of a multidisciplinary team involved in the treatment of a child or adolescent with cancer) in the psychosocial care of childhood cancer.<br>• Adequate strategies for addressing the mental health of caregivers and health personnel caring for children with cancer. | • By developing and adapting standards of psychosocial care for children and adolescents with cancer in the LAC region.<br>• By increasing the availability and dissemination of educational resources (guidelines, reports, and courses) on psychosocial care of childhood cancer for healthcare providers.<br>• By creating materials and documents that promote national regulations on psychosocial care. |
| **Nursing** | • Empowerment of the pediatric oncology nursing profession in the LAC region.<br>• Inclusion of basic pediatric oncology curricula in undergraduate nursing programs (e.g., signs/symptoms of childhood cancers).<br>• Formal specialization programs in LAC countries and models for ongoing professional development.<br>• Specialized education of nurses caring for children with cancer in multi-level practice settings (i.e., primary, secondary, tertiary).<br>• Integration of patient and family-centered care.<br>• Appropriate status recognition, salary incentives, and career advancement pathways for subspecialist pediatric oncology nurses in LAC.<br>• National and institutional policies for pediatric oncology nursing specialization (including minimum standards for education, staffing/non-rotation, and occupational safety, such as aspects stated in the International Society of Pediatric Oncology [SIOP] Baseline Nursing Standards and the Nurse Specialists of the GICC recommendations).<br>• Build research skills of nurses dedicated to childhood cancer in the LAC countries. | • By sharing success stories and experiences in pediatric oncology nursing from LAC countries.<br>• By assessing the scope of pediatric oncology nursing practice in the LAC region and defining professional competencies.<br>• By ensuring collaborative efforts to promote “good practice” implementation in the nursing care of the child and adolescent with cancer.<br>• By creating educational and communications resources available to nursing staff in Spanish and Portuguese.<br>• By promoting research initiatives through in-person and virtual workshops.<br>• By advocating to include nursing representatives as part of the national childhood cancer policy formulation team at a national level.<br>• Fostering the collaboration and participation of nursing in multicenter studies (implementation or research) on pediatric oncology nursing. |

(*Continued*)

**TABLE 1. (Cont.)**

| | Priorities (What is needed?) | Opportunities (How to achieve it?) |
|---|---|---|
| **Supportive care** | • Training of health professionals (with a special focus on providers working in pediatric services) in the supportive care of children and adolescents with cancer, including blood product transfusion therapy, oncological emergency management, and other aspects of oncological support.<br>• Strengthen the prevention and control of infections and treatment-related complications of children and adolescents during cancer treatment. | • By increasing the availability and dissemination of educational resources (guidelines, reports, and courses) on supportive care (basic/advanced level) for healthcare providers.<br>• By promoting national and regional collaborative work on supportive care in pediatric cancer in LAC countries.<br>• By developing a regional guideline on oral care of pediatric cancer patients.<br>• By developing materials to facilitate the guidance of parents and caregivers of children with cancer for the prevention of complications of infections and treatment-related complications. |

***Source:*** Prepared by the authors.

draft version was sent to the mentors, external collaborators, and experts from the competent units at PAHO and WHO (Mental Health and Substance Use Unit; Family, Health Promotion and Life Course; Nursing and Health Technicians; among others) for technical advice and suggestions. The PAHO cancer team oversaw the systematic incorporation and evaluation of the comments, suggestions, and modifications. A final version was sent to the PAHO editorial publication team for review and subsequent editing and formatting of the materials (including technical documents, virtual courses, communications resources, and others). The materials were circulated among the involved collaborators before publication on the PAHO website and communication channels.

## Dissemination and evaluation

The materials were disseminated through national and regional academic societies, PAHO, St. Jude, and partners' newsletters, websites, social media channels, and conference presentations. Evaluation of the preliminary impact of the regional resources was assessed by indicators according to the type of materials, within the consensus of the working committee.

## RESULTS

Between April and December 2021, 202 subject matter experts attended 43 online meetings to promote the dialogue between stakeholders to improve childhood cancer outcomes. Fourteen technical outputs were produced: four regional snapshots (palliative care, abandonment of treatment, early diagnosis, and nutrition), four technical documents (nutrition, oral care, pediatric oncology nursing, and psychosocial care), two virtual courses (early diagnosis and palliative care), one set of childhood cancer country profiles, and communication materials (one set of modules on palliative care and two regional campaigns). Details of the regional resources, including objectives, target audience, content, languages, and indicators are listed in Table 2 and Figure 3. The comprehensive results of the proposed indicators will be presented in a forthcoming publication.

## Technical documents

Four regional guidelines and reports on nutrition (*Nutritional care guide for pediatric cancer*, in Spanish) (12), oral care (*Oral care manual for pediatric cancer patients*, in Spanish) (13), pediatric oncology nursing (*The practice of pediatric oncology nursing in LAC*, in Spanish) (14), and psychosocial care (*Standards of psychosocial care in pediatric oncology*, in Spanish) (15) were developed and refined during several meetings of the working groups and in email discussions with the mentors and collaborators. These evidence-based technical documents are addressed to the multidisciplinary pediatric cancer care team, which includes medical, nutrition, and nursing staff, among other professionals. By February 2023, these technical documents had been collectively downloaded at least 7 379 times. One regional guideline on early diagnosis of childhood cancer (*Pocket manual/atlas for the early diagnosis of cancer in children and adolescents*, in Spanish) is still in the development phase and is planned to be launched in early 2024.

## Virtual courses

Two regional self-study, freely available virtual courses (*Virtual Course on Early Diagnosis of Cancer in Childhood and Adolescence* [16], in Spanish, Portuguese, and English; and *Palliative Care in Pediatric Cancer* [17], in Spanish) were developed and launched by the PAHO Virtual Campus for Public Health, with the support of the working committees, St. Jude Global Transversal Programs, and international partners. These courses are open to healthcare providers (physicians, nurses, and other professionals) and may be valuable tools for healthcare professionals who are seeking to improve their knowledge and skills in the early detection of childhood cancer and providing palliative care to children with cancer. By February 2023, there are at least 77 357 participants (55 549 already completed and certified) in the early diagnosis course, and 8 967 participants (3 877 already completed and certified) in the palliative care course. Two regional virtual courses (*Pediatric oncology support*, and *Pediatric cancer psychosocial care,* in Spanish) are still in the development phase, with their launch planned in late 2023.

## Regional snapshots

Four childhood cancer situation assessments in LAC (*Early diagnosis in pediatric oncology* [18], *Abandonment of treatment in pediatric oncology* [19], *Nutrition in pediatric oncology* [20], *and Palliative care in pediatric oncology* [21], in Spanish) were prepared to provide an in-depth analysis of the current state of these relevant issues in pediatric oncology in LAC. The documents discuss the challenges faced by healthcare providers in delivering high-quality early detection, palliative care, and nutritional care, and preventing abandonment of treatment, including lack of resources, limited access to specialized training, limited access to diagnostic technologies, and cultural barriers that may delay seeking and

**TABLE 2. PAHO childhood cancer regional materials and resources for healthcare professionals, policymakers, and the general population in Latin America and the Caribbean (licensed under open access)**

| Type of material | Title | Objective | Target audience | Languages | Cure*All* pillar/enabler |
|---|---|---|---|---|---|
| Technical documents | *Nutritional care guide for pediatric cancer* | To provide guidance to healthcare professionals on the nutrition care process of children with cancer, with the aim of identifying and improving their nutritional status, delivering adequate nutrition, minimizing treatment-related complications, and improving their overall quality of life. | Health professionals | Spanish | C – Centers of excellence<br>R – Regimens for treatment |
| Technical documents | *Oral care manual for pediatric cancer patients* | To provide healthcare professionals with practical guidance on how to prevent and manage oral complications associated with cancer treatment in children. The document aims to improve the oral health and quality of life of pediatric cancer patients by reducing the impact of oral complications. | Health professionals | Spanish | C – Centers of excellence<br>R – Regimens for treatment |
| Technical document | *The practice of pediatric oncology nursing in Latin America and the Caribbean* | To provide an overview of the current state of pediatric oncology nursing practice in the region. The ultimate goal of the document is to promote the development of effective pediatric oncology nursing practices in the region and to improve the outcomes and quality of life of pediatric cancer patients. | Health professionals<br>Policymakers | Spanish | C – Centers of excellence<br>A – Advocacy |
| Technical document | *Standards of psychosocial care in pediatric oncology* | To provide healthcare professionals with the knowledge and skills necessary to provide comprehensive psychosocial care to pediatric cancer patients and their families. The ultimate goal of the modules is to improve the psychosocial outcomes and quality of life of pediatric cancer patients and their families. | Health professionals | Spanish | C – Centers of excellence<br>R – Regimens for treatment<br>A - Advocacy |
| Virtual course | *Virtual Course on Early Diagnosis of Cancer in Childhood and Adolescence* | To provide healthcare professionals with the knowledge and skills necessary to effectively diagnose childhood cancer in its early stages. The ultimate goal of the course is to improve the outcomes and quality of life of pediatric cancer patients by promoting early diagnosis and timely access to appropriate care. | Health professionals | English<br>Spanish<br>Portuguese | C – Centers of excellence<br>U – Universal Health coverage<br>A – Advocacy |
| Virtual course | *Palliative Care in Pediatric Cancer* | To provide healthcare professionals with the knowledge and skills necessary to provide comprehensive palliative care to children with cancer and their families. The goal of the course is to improve the quality of life of pediatric cancer patients and their families by ensuring that they receive appropriate and compassionate care throughout their illness. | Health professionals | Spanish | C – Centers of excellence<br>U – Universal Health coverage<br>A – Advocacy |
| Epidemiological profiles | *Childhood Cancer Country Profiles* | To measure progress towards the goals of the Global Initiative for Childhood Cancer (GICC) and provide a comprehensive overview of childhood cancer care in each country, as well as regional and subregional profiles. The objective is to provide a valuable resource for identifying gaps and opportunities for improvement in childhood cancer care across Latin America and the Caribbean (LAC). | Policymakers<br>Health professionals | Spanish<br>English | C – Centers of excellence<br>U – Universal health coverage<br>R – Regimens for treatment<br>E – Evaluation and monitoring<br>L – Linked governance |
| Regional snapshots | *Early diagnosis in pediatric oncology: Situation in Latin America and the Caribbean* | To provide an overview of the current status of early diagnosis of childhood cancer in LAC, with a focus on identifying gaps and challenges that need to be addressed to improve the timely detection and treatment of pediatric cancer. | Policymakers<br>Health professionals | Spanish | U – Universal health coverage<br>R – Regimens for treatment<br>E – Evaluation and monitoring<br>A – Advocacy<br>L – Linked governance |
| Regional snapshot | *Abandonment of treatment in pediatric oncology: Situation in Latin America and the Caribbean* | To present an analysis of the situation of treatment abandonment in pediatric oncology in LAC, including its causes and consequences. The document aims to provide recommendations to improve the prevention and management of treatment abandonment, as well as to reduce its impact on children with cancer and their families in the region. | Policymakers<br>Health professionals | Spanish | U – Universal Health coverage<br>R – Regimens for treatment<br>E – Evaluation and monitoring<br>A – Advocacy<br>L – Linked governance |

(*Continued*)

**TABLE 2. (Cont.)**

| Type of material | Title | Objective | Target audience | Languages | Cure*All* pillar/enabler |
|---|---|---|---|---|---|
| Regional snapshot | *Nutrition in pediatric oncology: Situation in Latin America and the Caribbean* | To provide an overview of the nutritional situation of pediatric oncology patients in LAC. | Policymakers<br>Health professionals | Spanish | U – Universal Health coverage<br>R – Regimens for treatment<br>E – Evaluation and monitoring<br>A – Advocacy<br>L – Linked governance |
| Regional snapshot | *Palliative care in pediatric oncology: Situation in Latin America and the Caribbean* | To provide an overview of the situation of palliative care in pediatric oncology in the countries of LAC. | Policymakers<br>Health professionals | Spanish | U – Universal Health coverage<br>R – Regimens for treatment<br>E – Evaluation and monitoring<br>A – Advocacy<br>L – Linked governance |
| Materials for parents and caregivers | *Quality of Life Series for Children with Cancer: Modules on Pediatric Palliative Care* | To provide essential information to parents and caregivers of children with cancer about palliative and end-of-life care. The goal of this eight-module series is to improve patient families' health literacy levels toward palliative care, so that they become more willing to accept the early incorporation of palliative care in their child's care. | Parents, caregivers, and families of children affected by cancer | Spanish<br>Portuguese | C – Centers of excellence<br>U – Universal health coverage<br>A – Advocacy |
| Regional campaign | *Decide on time, a regional campaign to tackle childhood cancer treatment refusal* | The campaign underscores the significance of averting treatment rejection among a specific subgroup of patients (namely, children diagnosed with retinoblastoma and bone sarcomas, who require enucleation and amputation, respectively, for medical reasons). | Parents and caregivers of children affected by retinoblastoma and bone sarcomas | Spanish<br>English<br>French<br>Creole | A – Advocacy |
| Regional campaign | *Support Kids with Cancer, a regional campaign of early detection of childhood cancer* | To raise awareness of childhood cancer and to improve the knowledge on the symptoms and signs of cancer in children and adolescents. | General population (with special interest in parents and teachers)<br>Primary care providers | Spanish<br>English | A – Advocacy |

***Source:*** Prepared by the authors.

completing medical attention. The documents highlight the need for action to address these issues and provide recommendations for policymakers, health professionals, and other stakeholders to improve health outcomes in the region. By February 2023, these regional snapshots have been downloaded at least 1 073 times.

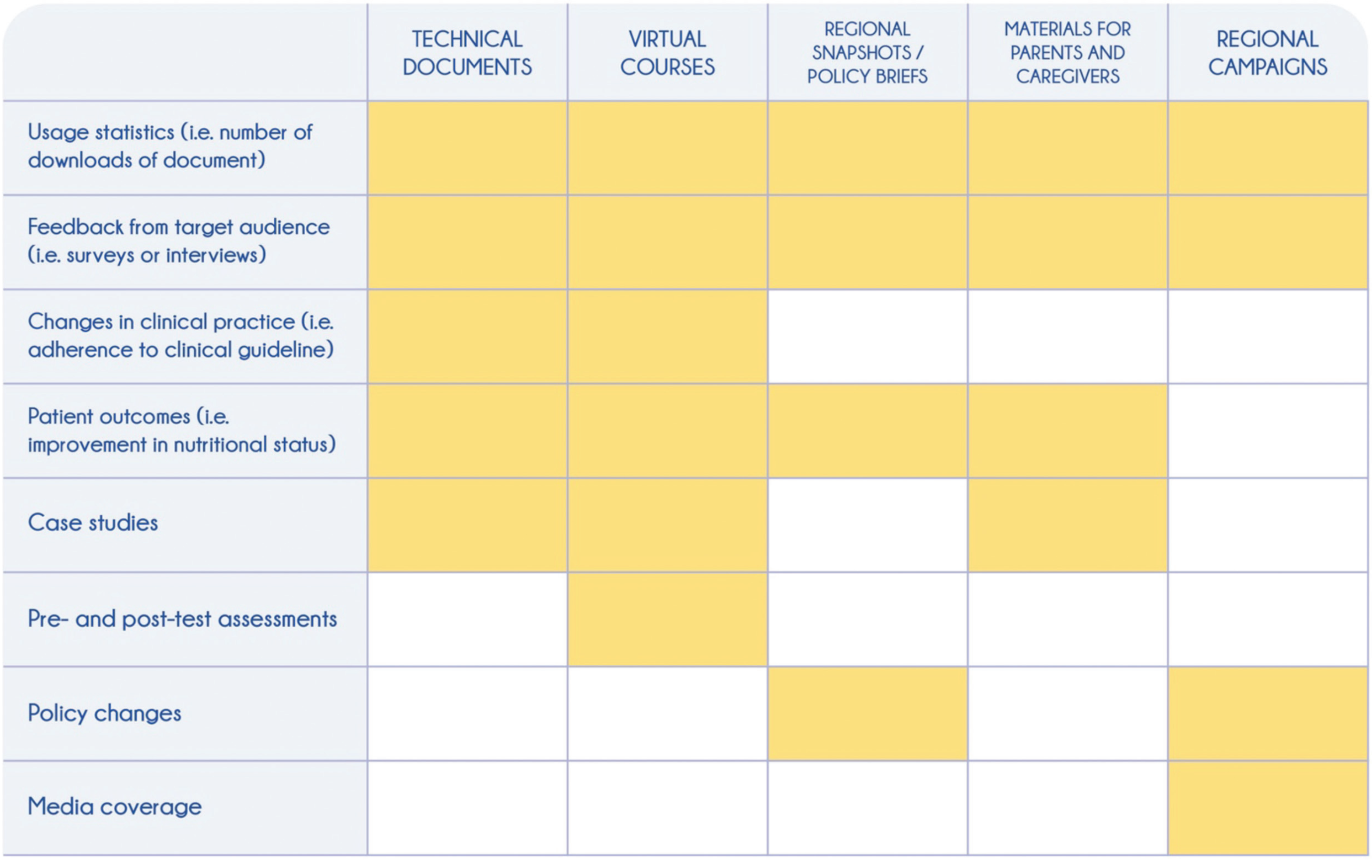
## Childhood cancer country profiles

The *Childhood Cancer Profiles* (4) for the Region of the Americas were developed to provide a comprehensive overview of childhood cancer care in the region and also in subregions and each LAC country. The profiles include a set of indicators that measure progress toward the goals of the GICC. These indicators are organized into four sections: burden of childhood cancer; survival and cancer registration; health system response for childhood cancers; and palliative care capacity. The burden of childhood cancer section includes indicators such as the number of new cases, deaths, and proportions for the six prioritized pediatric cancers in the WHO GICC (acute lymphoblastic leukemia, Burkitt's lymphoma, Hodgkin's lymphoma, retinoblastoma, Wilms tumor, and low-grade glioma). The survival and cancer registration section includes indicators such as net survival rates for these cancers and information related to pediatric cancer registries. The health system response section includes indicators such as providing essential medicines and technologies for childhood cancer treatment, specialized centers, and universal health coverage. Finally, the palliative care capacity section includes indicators such as the availability of pediatric palliative care teams. In Latin America and the Caribbean, 32 countries were included in this analysis. The data sources vary by indicator using the latest available year and are presented in each country's profile. The profiles serve as a valuable tool for identifying gaps and opportunities for improvement in childhood cancer care across the region. In addition, the information in these profiles can serve as a baseline to assess specific needs and results obtained on regional collaboration efforts, accelerating progress toward improving outcomes for children with cancer.

## Materials for parents and caregivers

PAHO, St. Jude Global Palliative Care Program, Together by St. Jude™ program (22), and the LAC working group on palliative care developed a comprehensive guide for families of children treated for cancer, on the delivery of palliative care (*Quality of Life Series for Children with Cancer: Modules on*

**Figure 3. Proposal for indicators for measuring the impact of PAHO childhood cancer regional materials in Latin America and the Caribbean**



| | TECHNICAL DOCUMENTS | VIRTUAL COURSES | REGIONAL SNAPSHOTS / POLICY BRIEFS | MATERIALS FOR PARENTS AND CAREGIVERS | REGIONAL CAMPAIGNS |
|---|---|---|---|---|---|
| Usage statistics (i.e. number of downloads of document) | 🟨 | 🟨 | 🟨 | 🟨 | 🟨 |
| Feedback from target audience (i.e. surveys or interviews) | 🟨 | 🟨 | 🟨 | 🟨 | 🟨 |
| Changes in clinical practice (i.e. adherence to clinical guideline) | 🟨 | 🟨 | | | |
| Patient outcomes (i.e. improvement in nutritional status) | 🟨 | 🟨 | 🟨 | 🟨 | |
| Case studies | 🟨 | 🟨 | | 🟨 | |
| Pre- and post-test assessments | | 🟨 | | | |
| Policy changes | | | 🟨 | | 🟨 |
| Media coverage | | | | | 🟨 |

***Note:*** Colored cells represent the proposed indicators for each item.
***Source:*** Prepared by the authors.

*Pediatric Palliative Care* (23), in Spanish and Portuguese). The guide consists of eight modules that cover a range of topics related to palliative care and quality of life, including symptom management, communication with patients and families, and considerations during end-of-life care. The resource is designed to be accessible and easy to use for parents and caregivers, with each module consisting of essential information to provide high-quality care to pediatric cancer patients and their families. To February 2023, these materials have been downloaded at least 2 825 times. Details about this resource will be presented in another article in this special supplement on childhood cancer. Additional regional educational material aiming to address treatment adherence (*Emely's suitcase,* in Spanish) is still in the development phase, with its launch planned in late 2023.

## Regional communication campaigns

Two regional childhood cancer campaigns were developed and jointly launched by PAHO, Childhood Cancer International, and the Together by St. Jude™ program. In February 2022, a communication campaign to address the refusal of treatment in patients with two of the most common types of childhood cancers – retinoblastoma and osteosarcoma – was launched in three countries in the region where the abandonment of treatment is a determining factor in achieving the cure of children with cancer (Bolivia, Haiti, and Peru). In these countries, nearly one-third of the cases of treatment abandonment in patients diagnosed with retinoblastoma and bone sarcomas are due to refusal of treatment at the time of the indication for amputation or enucleation, mainly due to parents' fear of the consequences of the treatment and mistrust in the health system. Audiovisual materials were developed in Spanish, English, French, and Creole. Additionally, on 15 February 2023, an important campaign to raise awareness of childhood cancer and to improve access to high-quality care for children with cancer in the region was launched. The campaign aims to raise awareness among the general population about childhood cancer's signs and symptoms, promote early detection and diagnosis, and advocate for greater investment in research and treatment. Materials are available in Spanish and English (10). During the launch month, the campaign videos were seen more than 11 916 times.

## DISCUSSION

This report highlights the crucial role of ongoing dialogue and commitment from PAHO, St. Jude, LAC working committees, and international collaborators in accelerating the implementation of the GICC. Through this example of collaboration, several resources of regional relevance have been appropriately developed, validated, and disseminated in the cultural context and main local languages of LAC (Spanish and Portuguese). The goal of the GICC is to strengthen health systems by improving the response capacity of PAHO/WHO Member States (8), including strategies to address the main contributors of morbidity and mortality in childhood cancer, including delayed diagnosis, treatment abandonment, malnutrition, suboptimal support, nursing, psychosocial and palliative care, among others (6, 7, 10). Currently, 17 governments in LAC (Argentina, Bolivia [Plurinational State of], Brazil, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Nicaragua, Panama, Paraguay, Peru, and, Suriname) are collaborating with PAHO and St. Jude in the implementation of the Cure*All* framework to reach the common objective of improving childhood cancer survival (9).

The results of this study also demonstrate the importance of a collaborative and multidisciplinary approach to the implementation of the GICC. The Cure*All* framework emphasizes the need for multidisciplinary and family-centered care for children with cancer (9). The LAC working groups have embraced this approach and have brought together healthcare professionals, policymakers, and other stakeholders to work toward a common goal. Several important models of collaboration have facilitated the development of resources and interventions reflecting the diverse engagement and expertise of the stakeholders involved, which can lead to more efficient and effective healthcare delivery (24–26). Collaboration also enables the sharing of best practices and the development of standardized approaches to healthcare interventions which must be prioritized in public health, particularly in resource-limited settings (27). Furthermore, the GICC can maximize the utilization of existing resources and enhance the efficiency of its interventions (28). This would ultimately contribute to the sustainability and scalability of the initiative in the region.

Political priority is a critical factor in the scale-up of childhood cancer care, and advocacy efforts targeting policymakers are crucial to increasing visibility (9). Local government authorities and policymakers have the power to allocate resources, set priorities, and develop policies and programs that can have a significant impact on the delivery of healthcare services. Effective advocacy efforts targeting policymakers including building alliances with key stakeholders, developing regional and national situation analysis and discussions, leveraging existing policies and programs, and utilizing media and other communication channels to raise awareness can increase political will, which in turn can lead to increased funding, improved policies and programs, and better outcomes for children with cancer. Global, regional, and national studies regarding factors contributing to childhood cancer outcomes in LMICs, such as delayed diagnosis (29), treatment refusal and abandonment (30), malnutrition (31), nurse staffing (32), and lack of supportive therapies and palliative care (33) are essential to provide critical information on the challenges facing children with cancer in these settings. Policymakers need to be aware of these factors and their impact on childhood cancer outcomes to develop effective policies and programs to address them. For example, policies aimed at improving early diagnosis and treatment could help reduce delayed presentation, while interventions aimed at improving access to nutrition and supportive care could help improve treatment-associated mortality. Likewise, information from the childhood cancer profiles and recommendations from regional and national reports and snapshots can help policymakers identify areas where resources should be focused to have the greatest impact on childhood cancer outcomes.

The development of resources targeted toward healthcare professionals is crucial to ensure that evidence-based practices are being implemented in the care of children with cancer. Such resources, including guidelines, training courses, and technical reports, provide healthcare professionals with the necessary tools and information to provide effective and efficient care that is tailored to the needs of their patients (9). The local context plays a significant role in the delivery of care. Therefore, these resources must be adapted to the specific needs of each community. The importance of developing and disseminating these resources cannot be overstated, as they play a critical role in advancing the field of childhood cancer care and improving the quality of life of children and their families.

Finally, educational and communication materials that aim to raise awareness and improve knowledge among parents, caregivers, and families of children affected by cancer are essential. Providing parents with evidence-based information and resources can improve their knowledge and skills, leading to better clinical outcomes for children with cancer. It can also help reduce stress and anxiety and improve the emotional well-being of caregivers (34).

It is important to note that the resources developed by the LAC working groups are not only relevant to the LAC region but also potentially applicable in other contexts. The content of these resources and the methodology used for their development might be useful in other contexts to be subsequently adapted at a local or national level. This highlights the potential for collaboration and knowledge sharing between different regions and countries to improve childhood cancer outcomes globally. Also, sustainability is a crucial factor in ensuring the success of interventions aimed at improving childhood cancer care in LAC. While implementation is an important step, efforts must be made to sustain these interventions over time to ensure their continued impact on the health outcomes of children with cancer. This requires a long-term commitment from policymakers and other stakeholders to allocate resources and develop policies and programs that support the ongoing delivery of healthcare services. By prioritizing sustainability, we can ensure that the progress made in improving childhood cancer care in LAC is not only implemented but sustained over time, leading to improved outcomes for children with cancer and their families (35).

Within the limitations of this study, it is important to mention that, even though the methodology of this study was prospective, it is difficult to assess whether there are better alternatives for the development of these types of materials. Moreover, the resources included in this publication have been developed according to a local context, but the applicability and diffusion in certain specific populations, such as native language contexts, must be considered and must be described for a more exhaustive evaluation. Finally, although a potential list of strategies to measure the impact of the developed resources is proposed in this study, a combination of these methods is likely to be used to measure the impact of these materials and to guide future revisions and updates to ensure their continued relevance and usefulness.

## Conclusion

In conclusion, the publicly available resources described in this article can support healthcare providers, policymakers, researchers, and other implementers in improving the care and quality of life of children and adolescents with cancer by applying evidence-based strategies to specific contexts. Similarly, these resources can facilitate the design of additional strategies to successfully develop, implement, and sustain interventions to improve childhood cancer care, reducing resource costs and improving health outcomes, especially related to morbidity and mortality from childhood cancer. Greater investments in childhood cancer projects and interventions (toward the reduction of abandonment of treatment, improving the opportunity and quality of diagnostics and treatment, integration of palliative care, nutrition, and nursing, among others), research, and innovation will promote equity and accelerate progress toward optimal outcomes for children and adolescents affected by cancer worldwide. Further research is needed to determine the impact of these strategies and resources on childhood cancer outcomes in LAC and other regions.

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# Colaborar para tener éxito: la Iniciativa Mundial contra el Cáncer Infantil en América Latina

**RESUMEN** La Iniciativa Mundial contra el Cáncer Infantil tiene como objetivo aumentar a nivel mundial la tasa de curación del cáncer infantil mediante la mejora del acceso a la atención de salud y de su calidad. La Organización Panamericana de la Salud (OPS), el St. Jude Children’s Research Hospital y los colaboradores han aunado esfuerzos para mejorar los resultados en la población infantil con cáncer en América Latina y el Caribe valiéndose del marco Cure*All*. En este artículo describimos el proceso de elaboración de recursos regionales destinados a acelerar la aplicación de la Iniciativa Mundial en América Latina y el Caribe.

En marzo del 2021, la OPS formó grupos de trabajo regionales para elaborar proyectos básicos que estuvieran en consonancia con los pilares y los elementos facilitadores del Cure*All*. De los diálogos regionales surgieron siete grupos de trabajo: detección temprana, enfermería, aspectos psicosociales, nutrición, tratamientos de apoyo, abandono del tratamiento y cuidados paliativos. La OPS organizó con regularidad reuniones virtuales en las que se contó con la tutoría y el apoyo de programas regionales o transversales del St. Jude Children’s Research Hospital y de mentores internacionales.

Entre abril y diciembre del 2021 hubo 43 reuniones virtuales a las que asistieron 202 expertos multidisciplinarios, con el objetivo de promover el diálogo entre las partes interesadas para mejorar los resultados en materia de cáncer infantil. Se elaboraron catorce productos técnicos: cuatro panoramas regionales, cuatro documentos técnicos, dos cursos virtuales, un conjunto de perfiles epidemiológicos de países, una serie con contenidos educativos para padres y cuidadores y dos campañas de comunicación.

El diálogo y el compromiso constantes de la OPS, el St. Jude Children’s Research Hospital, los comités de trabajo de América Latina y el Caribe y los colaboradores internacionales son las bases fundamentales para conseguir que se acelere la aplicación de la Iniciativa Mundial. Esto se puede lograr mediante la elaboración de materiales que resulten pertinentes a nivel regional y mundial. Son necesarias más investigaciones y evaluaciones para determinar el impacto que tienen estas estrategias y recursos en los resultados que se obtienen en el cáncer infantil en América Latina y el Caribe y en otras subregiones.

**Palabras clave** Neoplasias; salud infantil; colaboración intersectorial; planes y programas de salud; América Latina; región del Caribe.

# Colaboração para o sucesso: a Iniciativa Global para o Câncer Infantil na América Latina

**RESUMO** A Iniciativa Global para o Câncer Infantil tem como objetivo aumentar a taxa de cura de crianças com câncer no mundo todo, melhorando o acesso a cuidados e a qualidade da assistência médica. A Organização Pan-Americana da Saúde (OPAS), o St. Jude Children's Research Hospital (St. Jude) e colaboradores uniram esforços para melhorar o desfecho de crianças com câncer na América Latina e no Caribe (ALC) no âmbito do marco Cure*All*. Neste artigo, descrevemos o processo de desenvolvimento de recursos regionais com o objetivo de acelerar a implementação da Iniciativa na ALC.

Em março de 2021, a OPAS formou grupos de trabalho regionais para desenvolver projetos centrais alinhados com os pilares e facilitadores do Cure*All*. A partir das reuniões de diálogo regionais, foram criados sete grupos de trabalho: detecção precoce, enfermagem, atenção psicossocial, nutrição, cuidados de suporte, abandono do tratamento e cuidados paliativos. A OPAS organizou reuniões virtuais regulares sob a orientação e o apoio dos programas regionais e transversais do St. Jude e de mentores internacionais.

Entre abril e dezembro de 2021, 202 especialistas multidisciplinares participaram de 43 reuniões virtuais para promover o diálogo entre as partes interessadas a fim de melhorar os desfechos do câncer infantil. Foram produzidos 14 materiais técnicos: quatro panoramas regionais, quatro documentos técnicos, dois cursos virtuais, um conjunto de perfis epidemiológicos nacionais, uma série de conteúdo educacional para pais e cuidadores e duas campanhas de comunicação.

O diálogo e o compromisso contínuos da OPAS, do St. Jude, dos comitês de trabalho da ALC e dos colaboradores internacionais são bases essenciais para acelerar com sucesso a implementação da Iniciativa Global para o Câncer Infantil. Isso é possível por meio do desenvolvimento de materiais de relevância regional e mundial. São necessárias mais pesquisas e avaliações para determinar o impacto dessas estratégias e recursos nos resultados do câncer infantil na ALC e em outras regiões.

**Palavras-chave** Neoplasias; saúde da criança; colaboração intersetorial; planos e programas de saúde; América Latina; região do Caribe.