

# Collaborative effort to catalyze the implementation of the Global Initiative for Childhood Cancer in the Central American subregion

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## ABSTRACT

In Central America, childhood cancer is one of the leading causes of death. It is also a significant disease burden to health systems, with social and economic implications for families. The World Health Organization (WHO), the Executive Secretary of the Council of Ministers of Health of Central America and the Dominican Republic (SE-COMISCA), the Pan American Health Organization (PAHO), and St Jude Children's Research Hospital are working collaboratively to strengthen the health system's response to childhood cancer in Central America and the Dominican Republic. This collaboration's primary objective is to support the development of national pediatric cancer plans for each country in the subregion and improve overall survival rates and quality of care for children with cancer through a more comprehensive universal health coverage package. This collaborative effort has led to: (i) the development of childhood cancer national action plans; (ii) the launch of awareness and promotion campaigns; (iii) the design of childhood cancer educational material for children and their families; and (iv) a platform for professionals working in childhood cancer to share good practices and successful experiences. The countries of the subregion together with PAHO and St Jude Children's Research Hospital are working to develop standardized evidence-based clinical practice guidelines on childhood cancer for the region. This brief communication reports on this collaborative work.

## Keywords

Neoplasms; child health; clinical practice guideline; Central America.

In the Central American region, childhood cancer is one of the leading causes of death in children and adolescents (1). It is also a significant disease burden for health systems, with social and economic implications for families.

In high-income countries, more than 80% of children affected by cancer survive, but in many low- and middle-income countries, the survival rate is only about 20%. Preventable deaths due to childhood cancers in low- and middle-income countries result from under, incorrect or late diagnosis, difficulties accessing health care, dropping out of treatment, toxicity, and higher disease recurrence rates (1).

The World Health Organization (WHO), Executive Secretariat of the Council of Ministers of Health of Central America and the Dominican Republic (SE-COMISCA), Pan American Health Organization (PAHO), and St Jude Children's Research Hospital, are working collaboratively to strengthen the health system's response to pediatric cancer in the subregion. St Jude Children's Research Hospital is a collaborating center of the WHO's Global Initiative for Childhood Cancer and is recognized globally as a leader in the research and treatment of childhood cancer. This collaboration aims to support the creation of national pediatric cancer plans for the countries and

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improve overall survival rates and quality of care for children and adolescents with cancer by increasing access to and quality of health services, including supportive and palliative care, within the universal health coverage package (1).

Through this collaborative effort, decisive and effective steps have been taken, including:

- formulation of national action plans,
- launch of awareness and promotion campaigns,
- creation of educational material for children and their families, and
- development of peer dialogue platforms to share good practices and successful experiences.

Countries of the Central American Integration System (SICA) – Belize, Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama, and the Dominican Republic – plan to advance these efforts further by developing scientific-based standardized clinical practice guidelines for the Central America Region. This report describes the collaborative work between SE-COMISCA, PAHO, and St Jude Children’s Research Hospital to formulate these guidelines, which are still under development.

## BACKGROUND

Access to health care services is difficult for several diseases in Central America, including pediatric cancer. The scarcity of financial resources for the long-term sustainability of the health systems to improve early detection of childhood cancer affects survival rates in this vulnerable population. Additionally, public health authorities have focused the health budget on other prioritized health problems with greater morbidity, such as communicable diseases (1).

As indicated in the PAHO countries profiles (2), the lack of access to comprehensive care services for childhood cancer in Latin American countries is the primary reason for the overall net survival rate for cancer of 55%. In high-income countries, survival rates surpass 80%, reflecting the disparities in health care access (3).

In 2019, PAHO, SE-COMISCA, and St Jude Children’s Research Hospital led efforts with governmental and non-governmental actors that aimed to encourage joint work and prioritized actions to achieve a childhood cancer survival rate of at least 60% in Central America and the Dominican Republic by 2030, in line with WHO’s global initiative for childhood cancer (1). Among the outcomes was the regional initiative on pediatric cancer care in the SICA region for 2019–2030 (4).

The goals of the regional initiative are to boost political commitment to pediatric cancer diagnosis and treatment, to ensure the existence and implementation of standards and tools to guide the planning and application of interventions related to comprehensive pediatric cancer care, and to improve access to medicines and technologies for pediatric cancer care (3).

A significant milestone resulting from the initiative was the workshop on the subregional and national plan for pediatric cancer in 2019 in Costa Rica. The workshop was attended by those responsible for the national cancer programs of the ministries of health, the Association of Pediatric Hemato-Oncology of Central America, the Technical Commission on Chronic Diseases and Cancer of COMISCA, and SE-COMISCA. This workshop facilitated the integration of actions in the eight member countries of SICA.

In the workshop, participants reached a consensus on how to formulate the efforts on pediatric cancer in Central America and the Dominican Republic and the prioritization of tasks among the specialized technical actors, government representatives, and nongovernmental organizations.

This milestone was the beginning of continuous work led by SE-COMISCA, with technical support of PAHO in Central America and St Jude Children’s Research Hospital and strong commitment of officials of the ministries of health and members of the Association of Pediatric Hemato-Oncology of Central America. The initiative was approved by COMISCA in December 2019 (COMISCA Resolution 22-2019).

Since the approval of the initiative, national cancer plans have been developed in 50% of the SICA countries and are being prepared in the other countries. PAHO, St Jude Children’s Research Hospital, and SE-COMISCA maintain a working group that promotes the actions agreed upon in the initiative in each country. In the national plans, specific baseline actions to be carried out have been identified, together with their corresponding monitoring and evaluation components.

Regional and subregional institutions provide vital support to catalyze national efforts and advance the implementation of the initiative. The work will continue in collaboration with the Association of Pediatric Hemato-Oncology of Central America and the inclusion of other actors that could contribute to the process will be explored.

Guided by the initiative and recognizing the importance of regional clinical practice guidelines, the SE-COMISCA, PAHO, and the Central American Region team has started a systematic bibliographic review and has developed an operative scope of work proposal for the development of guidelines for the six index childhood cancers (acute lymphoblastic leukemia, Burkitt lymphoma, gliomas (low grade), Hodgkin lymphoma, retinoblastoma, and Wilms tumor). The WHO Global Initiative for Childhood Cancer selected the six index cancers based on various criteria. These criteria included the global incidence of cancers in children, the availability of effective treatments, diagnostic capacity, and existing resources to address each type of cancer. Focusing on these cancers allows efforts and resources to be directed to their prevention, early diagnosis, and treatment to improve the survival and quality of life of affected children.

A regional situational analysis has also been undertaken of human resources and infrastructure in regional pediatric oncology reference hospitals.

## RATIONALE FOR THE GUIDELINES

The Regional Initiative for Childhood Cancer Strategy in Central America is based on the PAHO/WHO CureAll technical package; this framework is composed of four pillars and three enablers. The first pillar is centers of excellence, and the development of the clinical practice guidelines is in line with this pillar and the need for timely diagnosis, treatment, and referral pathways. These guidelines will also support the training of human resources and the optimization of infrastructure and equipment.

The second pillar is universal health coverage which advocates for the financial coverage of diagnosis, treatment, and supportive and palliative care for pediatric cancer patients, and the inclusion of childhood cancer in health packages.

The third pillar is regimens of treatment, which supports the development of the clinical practice guidelines to ensure that good-quality medicines and supplies are available for management of pediatric cancer.

To develop the guidelines, the SE-COMISCA and PAHO team proposes the following process.

- Develop a scope of work proposal for the six index childhood cancers, evaluating resources available in the region and exploring the supply of essential medicines.
- Create a commission of childhood cancer experts for each of the six index cancers that will support their development.
- Use the PAHO/WHO Grading of Recommendations Assessment, Development and Evaluation (GRADE) methodology to guide the adaptation of guidelines (5).

## PROPOSAL FOR DEVELOPING REGIONAL CLINICAL PRACTICE GUIDELINES

### Scope of work

The guidelines will focus on the six index childhood cancers established in the WHO Global Initiative for Childhood Cancer and included in the regional initiative of Central America and the Dominican Republic. Additionally, the public health problems in Central America and the Dominican Republic will be defined. The proposed process divides the work into three phases.

**Phase 1.** For development of the Regional Clinical Practice Guidelines for Pediatric Cancer, the PAHO/WHO GRADE methodology will be used (Figure 1).

First, the group of professionals for each technical level should be defined and their profiles developed.

- a) Level 1. The initial development of the guidelines will require a multidisciplinary clinical team of pediatric haemato-oncologists, experts on each of the six index cancers, and epidemiologists.
- b) Level 2. The official review of the guidelines will require experts in GRADE methodology with a designated focal point.
- c) Level 3. Validation of the guidelines will require a team consisting of PAHO regional advisers, the COMISCA Technical Commission on Chronic Diseases and Cancer, SE-COMISCA, and the Presidency Pro-Tempore (a function exercised by a SICA member state for a period of 6 months for communication and coordination between governments and the departments and institutions of SICA for the development of the agenda on regional integration in the field of health).

The necessary tools for each level and the six cancers should be developed and a work schedule established. In addition, the resources and supply of essential medicines available in the region should be evaluated.

The above-mentioned technical teams should undertake the introductory virtual course on elaborating and adapting guides using the GRADE methodology in the PAHO virtual campus. The course addresses health professionals who develop guidelines or use evidence-informed recommendations for policy and practice in Latin American countries. Its objectives are

to: strengthen capacities in implementing the processes recommended by WHO/PAHO for developing guidelines and technical documents that consider scientific evidence; improve the competence of health professionals in the search and use of guidelines; improve knowledge and skills in the critical reading of guidelines and the processes of elaboration and adaptation of evidence-based guidelines using the GRADE methodology; and acquire the basic knowledge for the implementation of guidelines in the health context, including in the use of decision-making guides.

It is important to remember that that the guidelines must be updated in a period agreed upon by the subregional commission for childhood cancer, SECOMISCA, PAHO, and St Jude Children's Research Hospital.

The technical teams of the three levels should familiarize themselves with and use the relevant resources for the development of the the guidelines (6–9).

The technical teams should take the following steps.

1. Assess the need to develop a guideline. This analysis already exists on the part of the member countries of the subregion.
2. Set up a working group.
3. Search for existing clinical practice guidelines with strong evidence for adaptation.
4. Develop the guideline, identify clinical questions, and search, select, and analyze studies. If necessary, adapt the existing guidelines.
5. Write the first draft of the guidelines.
6. Send out the draft for external review and piloting.
7. Finalize the guidelines based on feedback.
8. Establish update periods based to new scientific evidence.

**Phase 2. Implementation.** The PAHO Subregional Office for Central America, in collaboration with SE-COMISCA, PAHO Regional Office, and St Jude Children's Research Hospital, has drafted an implementation plan grounded in the principles of implementation science, which is pivotal for the successful dissemination and adoption of childhood cancer treatment guidelines within health care systems. The multi-phased implementation strategy has four stages. In the first stage, known as pre-implementation assessment, there will be a thorough review of existing care protocols, gaps in clinicians' knowledge, and organizational readiness. This stage will use evaluative techniques, including SWOT analysis, stakeholder interviews, and focus group discussions, to assess accurately the existing health care landscape. The second stage, termed capacity-building, will prioritize educational initiatives for health care providers and the development of necessary infrastructural support, such as specialized electronic health record systems compatible with the new guidelines. The third stage, or pilot testing, will initially see the guidelines deployed on a small scale, with rigorous monitoring mechanisms to measure treatment adherence, patient outcomes, and clinician satisfaction, thereby facilitating real-time adjustments. The final stage, full-scale implementation, will expand the tested model across the entire health care network.

**Phase 3. Approval, dissemination, and updating of clinical practice guidelines.** Once standardized and agreed-upon, the guidelines will be submitted to COMISCA for approval

FIGURE 1. Map for the adaptation of guidelines



Source: PAHO (7).

for implementation across Central American countries and the Dominican Republic in alignment with the objectives of the SICA Member States. The childhood cancer treatment guidelines will be disseminated across the health care network, guided by a framework for continuous monitoring and periodic updates informed by ongoing data collection and analysis. This is a cyclical and adaptive approach, which allows for real-time refinements in both guideline implementation and dissemination. In terms of maintenance and updates, SE-COMISCA will take the lead, collaborating closely with the subregional commission for childhood cancer, PAHO, and St. Jude Children's Research Hospital, to ensure that the guidelines remain current, effective, and evidence-based.

## CONCLUSION

Developing subregional childhood cancer guidelines is important to increase the survival rate of children with cancer in SICA countries. The guideline proposal is strengthened by the existence of the long-established partnership between the subregional countries known as the Central American consortium—Asociación de Hemato-Oncología Pediátrica de

Centro América (9). The consortium includes care providers, and experts in the field of pediatric oncology and other subspecialists, who strive to provide adapted scientific-based evidence guidelines to improve the health outcomes of children with cancer and overcome the obstacles of working in resource-constrained settings. Implementing the clinical practice guidelines for childhood cancer is intended to increase awareness of potential effects of late diagnosis, and standardize and enhance follow-up care provided to pediatric cancer survivors throughout their life.

**Author contributions.** KEA conceived, planned, and coordinated the study and drafted the manuscript. ML Campos was involved in data collection and analysis. SF-A contributed to the study's conceptual framework and data collection. All authors reviewed and revised the manuscript and approved the final version.

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**Conflicts of interest.** None declared.

**Disclaimer.** The authors hold sole responsibility for the views expressed in the manuscript, which may not necessarily reflect the opinion or policy of the RPSP/PAJPH and/or the Pan American Health Organization (PAHO).

## REFERENCES

1. Pan American Health Organization. Iniciativa de Cáncer Pediátrico en Centroamérica [Pediatric Cancer Initiative in Central America] [Internet]. Washington, D.C.: PAHO; 2019 [cited: 2023 Aug 30]. Available from: <https://www.paho.org/es/temas/cancer/iniciativa-cancer-pediatico-centroamerica>
2. Pan American Health Organization. Childhood cancer country profiles 2021 [Internet]. PAHO; 2021 [cited: 2023 Aug 9]. Available from: <https://www.paho.org/en/childhood-cancer-profiles-2021>
3. Pan American Health Organization. Cancer in childhood and adolescence [Internet]. PAHO; 2023 [cited: 2023 Aug 9]. Available from: <https://www.paho.org/es/temas/cancer-ninez-adolescencia#:~:text=El%20c%C3%A1ncer%20infantil%20comprende%20numerosos,y%20el%20tumor%20de%20Wilms>
4. Sistema de la Integración Centroamericana. Iniciativa Regional para la Atención Integral del Cáncer Pediátrico en los países de la Región SICA, 2019–2030 [Regional Initiative for the Comprehensive Care of Pediatric Cancer in the countries of the SICA Region, 2019–2030]. El Salvador: SICA; 2019 [cited: 2013 Aug 30]. Available from: <https://www.paho.org/es/documentos/iniciativa-regional-para-atencion-integral-cancer-pediatico-paises-region-sica-2019-0>
5. Malmivaara A. Methodological considerations of the GRADE method. *Ann Med.* 2015;47(1):1–5. <https://doi.org/10.3109/07853890.2014.969766>
6. Pan American Health Organization. Strengthening national evidence-informed guideline programs: a tool for the adaptation and implementation of guidelines in the Americas. Washington, D.C.: PAHO; 2018 [cited: 2023 Aug 23]. Available from: <https://iris.paho.org/handle/10665.2/49145>
7. World Health Organization. WHO handbook for guideline development, 2nd edition. Geneva: WHO; 2014 [cited: 2023 Aug 23]. Available from: <https://apps.who.int/iris/handle/10665/145714>
8. Pan American Health Organization. Mapa para la adaptación de las guías [Map for guidelines adaptation] [Internet]. Washington, D.C.: PAHO [cited: 2023 Aug 23]. Available from: <https://guidelines-map.epistemonikos.org/#/es>
9. Schünemann H, Brożek J, Guyatt G, Oxman A, editors. Grade handbook. Grading of Recommendations, Assessment, Development and Evaluation. Version en Español GRADE Working Group; 2017 [cited: 2023 Aug 23]. Available from: <https://gdt.gradeapro.org/app/handbook/translations/es/handbook.html>
10. Barr RD, Klussmann FA, Baez F, Bonilla M, Moreno B, Navarrete M, et al. Asociación de Hemato-Oncología Pediátrica de Centro América (AHOPCA): a model for sustainable development in pediatric oncology. *Pediatr Blood Cancer.* 2014;61(2):345–54. <https://doi.org/10.1002/xbc.24802>

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## Esfuerzo de colaboración para impulsar la aplicación de la Iniciativa Mundial contra el Cáncer Infantil en la subregión de Centroamérica

### RESUMEN

En Centroamérica, el cáncer infantil es una de las principales causas de muerte. La enfermedad también supone una carga considerable para los sistemas de salud y tiene implicaciones sociales y económicas para las familias. La Organización Mundial de la Salud (OMS), la Secretaría Ejecutiva del Consejo de Ministros de Salud de Centroamérica y República Dominicana (SE-COMISCA), la Organización Panamericana de la Salud (OPS) y el St Jude Children's Research Hospital están trabajando conjuntamente para fortalecer la respuesta de los sistemas de salud frente al cáncer infantil en Centroamérica y República Dominicana. El objetivo principal de esta colaboración es respaldar la elaboración de un plan nacional sobre el cáncer pediátrico para cada país de la subregión y mejorar las tasas de supervivencia global y la calidad de la atención que se presta a la población infantil con cáncer mediante un programa más completo de cobertura universal de salud. Este esfuerzo de colaboración ha dado lugar a: a) la elaboración de planes de acción nacionales sobre el cáncer infantil; b) la puesta en marcha de campañas de concientización y promoción; c) el diseño de materiales educativos sobre el cáncer en la infancia para la población infantil y sus familias; y d) una plataforma para que los profesionales que trabajan en cáncer infantil intercambien buenas prácticas y experiencias exitosas. Los países de la subregión, junto con la OPS y el St Jude Children's Research Hospital, están trabajando en la elaboración para Centroamérica de unas directrices de práctica clínica sobre cáncer infantil que estén estandarizadas y basadas en la evidencia.

**Palabras clave** Neoplasias; salud Infantil; guía de práctica clínica; Centroamérica.

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## Esforço colaborativo para catalisar a implementação da Iniciativa Global para o Câncer Infantil na sub-região da América Central

### RESUMO

Na América Central, o câncer infantil é uma das principais causas de morte. O câncer também representa uma carga importante de doença para os sistemas de saúde, com implicações sociais e econômicas para as famílias. A Organização Mundial da Saúde (OMS), a Secretaria Executiva do Conselho de Ministros da Saúde da América Central e da República Dominicana (SE-COMISCA), a Organização Pan-Americana da Saúde (OPAS) e o St Jude Children's Research Hospital estão trabalhando em colaboração para fortalecer a resposta do sistema de saúde ao câncer infantil na América Central e na República Dominicana. O principal objetivo dessa colaboração é apoiar o desenvolvimento de planos nacionais para o câncer pediátrico em cada país da sub-região e melhorar as taxas gerais de sobrevivência e a qualidade do atendimento a crianças com câncer por meio de um pacote mais abrangente de cobertura universal de saúde. Os resultados desse esforço colaborativo foram: *a)* desenvolvimento de planos de ação nacionais para o câncer infantil; *b)* lançamento de campanhas de conscientização e promoção; *c)* criação de material educativo sobre o câncer infantil para as crianças e suas famílias; e *d)* uma plataforma para que os profissionais que trabalham com câncer infantil compartilhem boas práticas e experiências bem-sucedidas. Os países da sub-região, juntamente com a OPAS e o St Jude Children's Research Hospital, estão trabalhando para desenvolver diretrizes regionais de prática clínica para o câncer infantil padronizadas e baseadas em evidências.

**Palavras-chave** Neoplasias; saúde da criança; guia de prática clínica; América Central.

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