

Regional collaboration for the development of national childhood cancer plans in Latin America and the Caribbean

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ABSTRACT

This article aims to describe the activities conducted by the National Childhood Cancer Plan Working Group to support the development of national childhood cancer plans in Latin America and the Caribbean in the period 2019–2022, and to present the stage of plan development. The Working Group activities were supported by the Pan American Health Organization and St. Jude Children's Research Hospital, which is the World Health Organization (WHO) Collaborating Centre for Childhood Cancer. Year after year, the workshops and activities developed with the Working Group mobilized key stakeholders: pediatric oncologists, representatives of the Ministry of Health, foundations supporting childhood cancer initiatives, and hospital administrators. As of February 2023, one regional framework is in place, approved by the Council of Ministries of Health of Central America and the Dominican Republic, nine countries are currently implementing national plans or laws that include childhood cancer, and ten countries are writing new plans. The WHO three-step framework helped to guide the Working Group activities. All plans were supported by a situational analysis, which highlighted the importance of having systematized data for evidence-based policies. To increase implementation success, an accompanying budget and timeline help to ensure the adequate implementation of the interventions. More than anything, committed stakeholders remain the most fundamental element to successfully write and approve a national childhood cancer plan. This is an opportunity to share these countries' experience so the strategy can be adapted to support other countries developing a childhood cancer plan and extended to other public health areas.

Keywords

Neoplasms, prevention & control; child health; health programs and plans; health policy; health planning; Latin America; Caribbean region.

Latin America and the Caribbean is one of the regions with the most inequity in childhood cancer survival (1). Governments can bridge this gap in a cost-effective manner with strategies to improve access to diagnostics and treatment – starting with prioritizing childhood cancer in the public health agenda (2).

National childhood cancer plans (NCCPs) are documents that guide the implementation of evidence-based interventions for childhood cancer on a national level. By organizing the cancer strategy while being cognizant of the broader national health priorities, cancer control plans define objectives and targets to

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improve cancer diagnosis and treatment, and prevent unnecessary program overlap and resource competition (3). Depending on a country's health system and policy structure, these documents can either be a plan dedicated exclusively for childhood cancer control, or a general cancer or noncommunicable disease plan with dedicated chapters or interwoven sections on children and adolescents.

Although childhood cancer is a public health problem, advocates face challenges such as competing health problems, limited resources, and certain specificities in the care of cancer in children and adolescents. The World Health Organization (WHO) recommends the involvement of key stakeholders – such as pediatric oncologists, representatives of the Ministry of Health, foundations supporting childhood cancer initiatives, and hospital administrators – early in the

planning process to create a sense of ownership and commitment to the plan's implementation, and to pool existing resources and network (3, 4). Although in Latin America and the Caribbean the number of countries with a plan or law that includes childhood cancer doubled in the past five years to a total of 13 countries (Figure 1), they are still the minority in the region.

Resulting from the regional collaborative work between Asociación Hemato-Oncológica Pediátrica Centroamericana (AHOPCA), St. Jude Children's Research Hospital (St. Jude), and the Pan American Health Organization (PAHO), in 2019 eight countries started a Working Group whose aim was to develop childhood cancer control plans. With the launch of the Global Initiative for Childhood Cancer (GICC) in 2018, more countries joined the Working Group. The CureAll framework is a coordinated operational approach to support countries strengthening their childhood cancer programs. The CureAll framework is composed of four pillars (Centers of Excellence, Universal Health Coverage, Regimens of Treatment, and Evaluation and Monitoring), and three enablers (Advocacy, Leveraged Financing, Linked Governance) (4). The launch of the GICC established a global goal for improving childhood cancer survival and commitment from countries who joined the Initiative to achieve it, adding the topic to the world health agenda. In the CureAll framework, the development of NCCP is part of the last enabler *Linked Governance* and one of the 10 core projects. As such, GICC's expected deliverables include resources and technical support to facilitate the writing process.

Moreover, supporting countries to integrate childhood cancer in NCCPs is one of the engagements of St. Jude as the WHO Collaborating Centre for Childhood Cancer (5). Core activities in the appointment – which began in 2018 and was extended in 2022 – include supporting WHO to 1) integrate childhood cancer in NCCPs through tools or frameworks for prioritization, costing, and monitoring and evaluation; 2) develop tools and platforms for innovation and diffusion in childhood cancer management, research, and education; and 3) strengthen childhood cancer control through technical support, training, and stakeholder engagement (6). The work with international partners also added to national advocacy efforts and provided access to additional resources such as funding, tools, and technical expertise to write the plans.

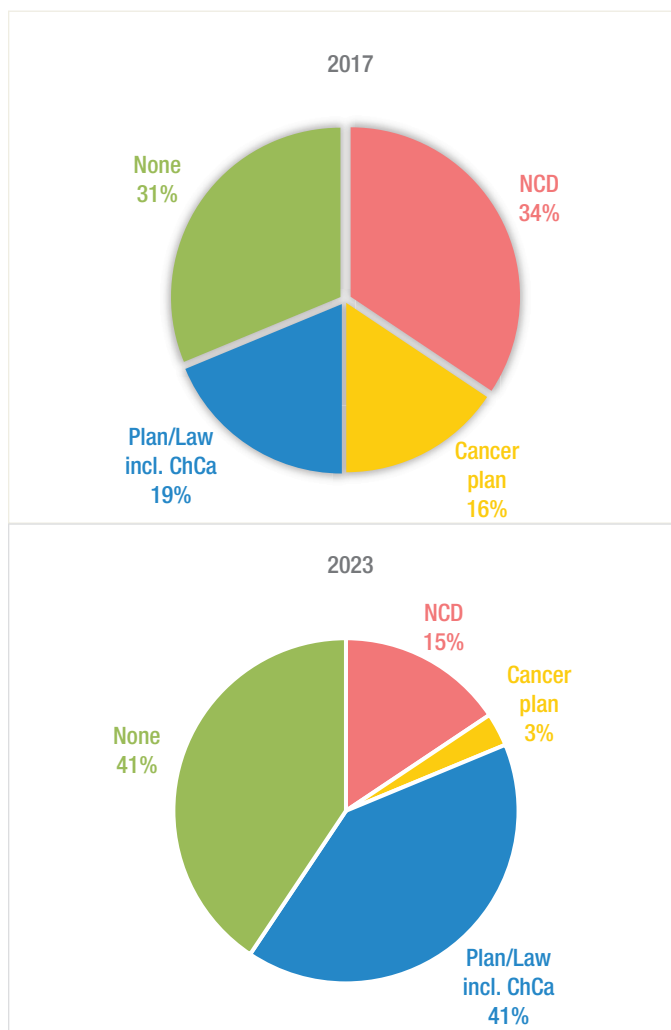
This article aims to describe the activities developed by the Working Group to develop the documents in eight countries in the period 2019–2022 and the stage of plan development.

MATERIALS AND METHODS

In 2017, PAHO and St. Jude organized regional workshops to support eight countries (Costa Rica, Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Nicaragua, and Panama) in strengthening their health systems and improving outcomes for children and adolescents with cancer. Year after year, these workshops mobilized key stakeholders: pediatric oncologists, representatives of the Ministry of Health, foundations supporting childhood cancer initiatives, and hospital administrators. Using design thinking methods, these workshops used a participatory process to identify national and regional initiatives focused on improving childhood cancer care.

As a result of these joint efforts, in February 2019, during the fourth St. Jude Global Alliance Central America and Caribbean

FIGURE 1. Development of national cancer control plans (including childhood cancer) in Latin America and the Caribbean, 2017 vs 2023, 32 countries



Note: NCD, noncommunicable diseases plan; ChCa, childhood cancer
Sources: St. Jude Children's Research Hospital, Department of Global Pediatric Medicine, Health Systems Unit [Internet]. St. Jude Global Policy Monitor. Memphis: St. Jude; 2023 [accessed 2023 Jan 10]. Available from: <https://www.stjude.org/global/sjcares/policies.html>.
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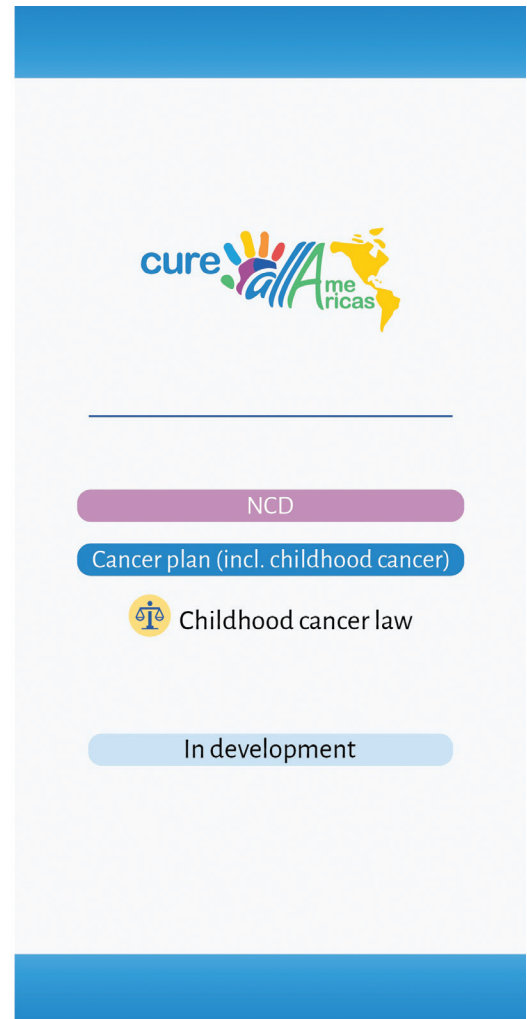
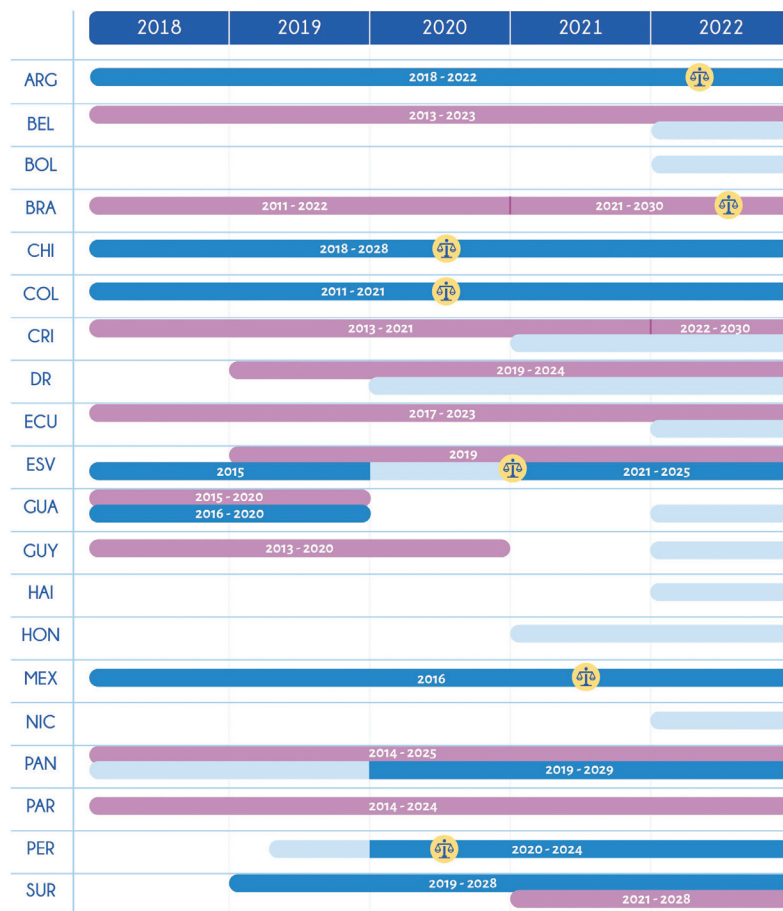
meeting in Costa Rica, participants unanimously recognized the need and expressed their commitment to develop NCCPs. Country teams reached this consensus after collaboratively mapping patients' journeys and understanding the challenges faced by families. A Childhood Cancer Plan Working Group was formed and participated in a second workshop in July to guide and facilitate the development of these documents with the support of the WHO three-step framework (3):

Step 1: Where are we now? The multistakeholder country team involved in the Working Group activities was composed of representatives from the Ministry of Health, pediatric oncologists, foundations, nongovernmental organizations, PAHO country office and, upon country request, a technical consultant hired by PAHO to guide and write the document. In most countries, the Ministry of Health assigned an advisory team at the ministerial level to lead and supervise the plan's development

and support its integration with other efforts. The first step was to conduct a situational analysis of the status of pediatric cancer care in the country. Countries applied different tools to perform this evaluation such as self-selected indicators, templates shared by PAHO and St. Jude, and the St. Jude Pediatric Oncology Facility Integrated Local Evaluation Tool (PrOFILE). In common, all of them listed the opportunities to improve childhood cancer care as an output. Upon country request, PAHO and St. Jude supported countries with tools and facilitated the situational analysis. To provide a baseline and identify shared regional needs, PAHO published the profiles of 25 countries in the region (1). The documents offer an overview of the main indicators concerning burden of childhood cancer and health system capacity.

Step 2: Where do we want to be? Time to establish the plan's objectives. Following the WHO Collaborative Centre

FIGURE 2: Regional Global Initiative for Childhood Cancer Working Group for Latin America and the Caribbean – national childhood cancer plan stage



Note: ARG, Argentina; BEL, Belize; BOL, Bolivia; BRA, Brazil; CHI, Chile; COL, Colombia; CRI, Costa Rica; DR, Dominican Republic; ECU, Ecuador; ESV, El Salvador; GUA, Guatemala; GUY, Guyana; HAI, Haiti; HON, Honduras; MEX, Mexico; NIC, Nicaragua; PAN, Panama; PAR, Paraguay; PER, Peru; SUR, Suriname. NCD, noncommunicable diseases plan.
Sources: Information about childhood cancer plan current stage was provided by Ministry of Health representatives in the Working Group. Published plans were accessed at: St. Jude Children's Research Hospital, Department of Global Pediatric Medicine, Health Systems Unit [Internet]. St. Jude Global Policy Monitor. Memphis: St. Jude; 2023 [accessed 2023 Jan 10]. Available from: <https://www.stjude.org/global/sjcares/policies.html>; and International Cancer Control Partnership [Internet]. International Cancer Control Partnership Portal. National Plans. Geneva: ICCP; 2023 [accessed 2023 Jan 10]. Available from: <https://www.iccp-portal.org/map>.

framework (5), the main role of St. Jude and PAHO was to provide frameworks and tools to conduct these activities. The most commonly used tools were the Country Collaboration for Childhood Cancer Control (C5) and Digest tools, developed by St. Jude, and the WHO Costing Tool. Respectively, these tools support countries to map health systems needs and prioritize strategic activities, to evaluate the content of their plans, and to prepare a budget for their action plan. Implementation of these tools can be in a cohort or individual country models, upon the issue of a support request by the Ministry of Health to PAHO.

Step 3: How do we get there? Includes writing the action plan, validation from key stakeholders and authorities, and publishing the document. In addition to participating in the regional workshops, country teams also organized national activities to collect feedback on their proposed plan and obtain validation or endorsement from authorities and key stakeholders.

To ensure shared decision-making and stakeholder engagement, during all steps the group favored meetings and workshops using design thinking methods. With the COVID-19 pandemic starting in 2020, meetings and exercises became virtual. For remote workshops, video conference platforms (Webex, Zoom, and Microsoft Teams) were used, as well as MURAL (mural.com), a digital interactive whiteboard.

As the development of an NCCP became one of the GICC's priority projects in the Americas, the movement gained track as countries formed teams and developed proposals. It was in this context that Argentina, Belize, Bolivia, Brazil, Chile, Colombia, Ecuador, Guyana, Mexico, Paraguay, Peru, and Suriname – in various stages of the process, and some with childhood cancer laws – joined the Working Group on childhood cancer plans.

The stage of each country's NCCP in this article was informed by the assigned Ministry of Health representative in the Working Group to the authors. Participation in activities was informed by workshop reports.

RESULTS

Based on the framework described, as of February 2023, ten countries in the Working Group are in the writing process and nine have a published pediatric cancer plan or law (Figure 2). This section details the activities conducted in each of the steps.

Step 1: Where are we now?

- In 2019, Costa Rica, Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Nicaragua, and Panama used a situational analysis tool together during the previously described workshops.
- In 2021, Chile and Peru applied the St. Jude Pediatric Oncology Facility Integrated Local Evaluation Tool (PrO-FILE), a self-assessment tool that provides a full evaluation of health system delivery.
- In 2022, Belize, Colombia, and Suriname conducted a national situational analysis focused on childhood cancer care to identify the specific needs for this population. In Colombia, this evaluation was part of the Integrated Mission of the Programme of Action for Cancer Therapy (imPACT) Review, applied with the support from the International Atomic Energy Agency (IAEA).
- Ecuador and Paraguay are currently planning their assessments.

Step 2: Where do we want to be?

To work on action plan development, between 2019 and 2022 St. Jude and PAHO offered methodological and/or financial support to execute 13 workshops. During these activities, teams evaluated the results from their chosen situation analysis tool using the Health Systems Plus framework adapted for children with cancer (6). Together, national stakeholders would agree on priorities and interventions. The following workshops were held during this period:

- Three regional workshops with country teams from Costa Rica, Dominican Republic, El Salvador, Guatemala, Haiti, Honduras, Nicaragua, and Panama. Two of these workshops were held in person in 2019 in Costa Rica (as described previously). The last regional one was the virtual workshop “How I Live” in 2021, which, using story-telling techniques and stakeholder mapping, supported teams to continue developing their action plans and to advocate for prioritized interventions.
- Two GICC workshops targeted the Caribbean nations of the Bahamas, Barbados, Belize, Guyana, Jamaica, Saint Lucia, Saint Vincent and the Grenadines, Suriname, and Trinidad and Tobago. The first one was held in person in Trinidad and Tobago in 2020, and a virtual workshop followed in 2021 to establish regional priorities.
- Eight national workshops: in Peru (in 2019 in person and 2020 virtually), Brazil (virtually in 2021), Chile (in person in 2022), Colombia (in person in 2022), Costa Rica (in person in 2022), Panama (in person in 2022), and Uruguay (virtually in 2022).
- Belize, Dominican Republic, and Suriname are planning to organize action plan workshops during 2023.

Step 3. How do we get there?

Based on the identified regional priorities during the July 2019 workshop, on 11 December 2019 the Council of Ministries of Health of Central America and the Dominican Republic (COMISCA), during their annual meeting, approved the Regional Initiative for the Comprehensive Approach of Cancer in Children and Adolescents (7). On a national level, country teams are responsible for writing the document to be submitted to the authorities. To support the NCCP writing process, the PAHO country offices hired consultants in Bolivia, Chile, Costa Rica, Dominican Republic, Guatemala, Haiti, and Honduras dedicated to writing a childhood cancer plan using funds from the GICC upon country request.

Finally, individualized technical assistance from PAHO and St. Jude was also available upon request. A country team, together with the PAHO country office, needed to formally reach out to PAHO headquarters to request technical assistance. A meeting between country team, PAHO country office and headquarters, and St. Jude team would follow, where expectations, deliverables, and timelines were agreed upon between the stakeholders.

DISCUSSION

The journey to an NCCP in the eight countries that first started to collaborate with PAHO and St. Jude evolved in an

organic way. It began from a patient-centered approach, where the patient's journey through care delivery highlighted that childhood cancer challenges could only be addressed collaboratively and via national-level strategies. The annual meetings that began in 2017 were composed mainly of pediatric oncologists. However, they progressively integrated other national stakeholders as it became clear that other sectors such as foundations, hospital administrators, and Ministry of Health officials needed to be involved to develop a technically solid proposal (3), and the group noticed they did not necessarily have existing platforms to connect.

The results of the situational analysis implemented in 2019 and later efforts supported the development of NCCP in all eight countries, using a standardized methodology to identify gaps/needs, available resources, and set objectives and targets across the continuum of cancer care. Two of these countries (El Salvador and Panama) are already implementing their childhood cancer plans, following government endorsement and provision of resources for implementation. Existing technical-academic collaborations in the region supported strategies to strengthen the region's health systems and identify priorities to be included in the NCCPs (6).

Different countries joined the Working Group with an NCCP or law already written (Argentina, Barbados, Brazil, Chile, Colombia, Jamaica, Mexico, and Suriname). In these cases, countries usually requested a technical review of the document or support with its implementation and/or localization (e.g., to draft a state or municipal level plan). Other countries joined first the Working Group and later signed the letter to become part of the Global Initiative (such as Belize and Guyana), suggesting that the topic can also be a resource for advocates to bring childhood cancer to the national authorities' agenda. Engagement from the Ministry of Health happened at different stages, with foundations also playing leading roles in the writing process as seen in Argentina, Brazil, and Honduras.

Each country's step-by-step journey to its final childhood cancer plan varied, depending on health system organization, resources, and political momentum. Advocacy was constant to keep childhood cancer in the political national agenda (8), and the engagement with COMISCA and the GICC brought awareness to governments to support childhood cancer plans. The collaboration with international partners like PAHO and St. Jude added to national advocacy efforts and offered additional solutions for needs that emerged along the way; for example, with funds for hiring a specialized consultant to write the plan and support with methodologies to prioritize childhood cancer

interventions (6). Until reaching our shared goal for 2030, PAHO and St. Jude will continue to offer technical assistance as needed to support the development of regional tools and trainings, and to strengthen partnerships with other organizations working with childhood cancer.

Further research includes documenting the process in each country to understand the barriers and facilitators to develop and implement NCCPs, and how countries navigate the steps from their situational analysis to implementing an action plan. It is hoped these processes can support countries who are considering writing an NCCP and also experts working in different areas, particularly other cancer types and noncommunicable diseases.

Potential points of interest for other health programs include the participative methodology that connected multiple actors involved with a certain priority. To successfully write the NCCP, a smaller multistakeholder team conducted strategic activities to plan and validate it. All plans were supported by a situational analysis, which highlighted the importance of having systematized data for evidence-based policies. To increase implementation success, an accompanying budget and timeline help to ensure the adequate implementation of the interventions (3). More than anything, committed stakeholders remain the most fundamental element. The journey to write a childhood cancer plan was not only about having the right idea but also about finding the right moment and the right people to make a vision a reality.

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Conflict of interests. None declared.

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Colaboración regional para la formulación de planes nacionales contra el cáncer infantil en América Latina y el Caribe

RESUMEN

En este artículo se describen las actividades realizadas por el grupo de trabajo del plan nacional contra el cáncer infantil dirigidas a brindar apoyo para la formulación de planes nacionales contra el cáncer infantil en América Latina y el Caribe en el período 2019-2022, así como la presentación de la etapa de formulación de los planes. Las actividades del Grupo de Trabajo contaron con el apoyo de la Organización Panamericana de la Salud y el St. Jude Children's Research Hospital, que es el centro colaborador de la Organización Mundial de la Salud (OMS) contra el cáncer infantil. Año tras año, los talleres y actividades llevados a cabo con el grupo de trabajo han logrado convocar a las principales partes interesadas: especialistas en oncología pediátrica, representantes del Ministerio de Salud, fundaciones que apoyan iniciativas contra el cáncer infantil y gerentes de los hospitales. Desde febrero del 2023, existe un marco regional, aprobado por el Consejo de Ministerios de Salud de Centroamérica y República Dominicana; nueve países ya están aplicando planes o leyes nacionales en los que se incluye el cáncer infantil, y diez países están redactando nuevos planes. Para orientar las actividades del Grupo de Trabajo, se recurrió al marco en tres pasos de la OMS. Todos los planes se sustentaron en un análisis de situación lo que subraya la importancia de contar con datos sistematizados para que las políticas puedan estar basadas en evidencias. Asimismo, si se pretende aumentar el éxito de la aplicación, sería conveniente contar con un presupuesto y un cronograma que aseguren la aplicación adecuada de las intervenciones. Las partes interesadas implicadas siguen siendo, ante todo, el componente más trascendente en la redacción y aprobación exitosa de un plan nacional contra el cáncer infantil. Esta es una oportunidad para transmitir la experiencia de estos países, con el fin de que la estrategia pueda adaptarse para brindar apoyo a otros países que estén elaborando un plan contra el cáncer infantil y que puede hacerse extensiva a otros ámbitos de la salud pública.

Palabras clave

Neoplasias, prevención & control; salud infantil; planes y programas de salud; política de salud; planificación en salud; América Latina; región del Caribe.

Colaboração regional para o desenvolvimento de planos nacionais de combate ao câncer infantil na América Latina e no Caribe

RESUMO

Este artigo visa a descrever as atividades realizadas pelo Grupo de Trabalho para Planos Nacionais de Combate ao Câncer infantil a fim de prestar apoio ao desenvolvimento de planos nacionais de combate ao câncer infantil na América Latina e no Caribe no período de 2019 a 2022 e apresentar a atual fase de desenvolvimento dos planos. As atividades do Grupo de Trabalho receberam apoio da Organização Pan-Americana da Saúde e do St. Jude Children's Research Hospital, o Centro Colaborador em Câncer infantil da Organização Mundial da Saúde (OMS). Ano após ano, as oficinas e atividades desenvolvidas com o Grupo de Trabalho mobilizaram as principais partes interessadas: oncologistas pediátricos, representantes dos ministérios da saúde, fundações que apoiam iniciativas de combate ao câncer infantil e administradores de hospitais. Até fevereiro de 2023, havia uma estrutura regional em vigor aprovada pelo Conselho de Ministros da Saúde da América Central e da República Dominicana, nove países estavam implementando planos ou leis nacionais que incluíam o câncer infantil e dez países estavam elaborando novos planos. A estrutura de três etapas da OMS ajudou a orientar as atividades do Grupo de Trabalho. Todos os planos estavam embasados em uma análise situacional, o que destacou a importância de dispor de dados sistematizados para políticas baseadas em evidências. Para aumentar o sucesso da implementação, um orçamento e um cronograma correspondentes ajudam a garantir a implementação adequada das intervenções. Acima de tudo, o compromisso das partes interessadas continua sendo o elemento mais fundamental para elaborar e aprovar com sucesso um plano nacional de combate ao câncer infantil. Esta é uma oportunidade de compartilhar a experiência desses países para que a estratégia possa ser adaptada a fim de apoiar outros países na elaboração de um plano de combate ao câncer infantil e possa ser estendida a outras áreas de saúde pública.

Palavras-chave

Neoplasias, prevenção & controle; saúde da criança; planos e programas de saúde; política de saúde; planejamento em saúde; América Latina; região do Caribe.
