PAN AMERICAN JOURNAL OF PUBLIC HEALTH 100 YEARS

Brief communication

Strengthening public health policies for childhood cancer: Peru's achievements through the WHO Global Initiative for Childhood Cancer

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Suggested citation Maradiegue E, Pascual C, Vasquez L, Maza I, Ugaz C, Montoya J, et al. Strengthening public health policies for childhood cancer: Peru's achievements through the WHO Global Initiative for Childhood Cancer. Rev Panam Salud Publica. 2023;47:e132. https://doi.org/10.26633/RPSP.2023.132

ABSTRACT

Objective. To report the progress in Peru, since June 2019, in the implementation of the World Health Organization Global Initiative for Childhood Cancer using the Cure*All* framework, which can be replicated in low- and middle-income countries.

Methods. A mixed method was used of participatory and documentary evaluation. The participatory evaluation included stakeholders from various government institutions, nonprofit organizations, and international partners. The documentary aspect consisted of a review of data on the regulatory environment, national projects, and interventions implemented. The Ministry of Health engaged more than 150 participants to form working committees, which have developed policy and regulatory documents to strengthen care services.

Results. Achievements include a decrease in the national treatment abandonment rate from 18.6% to 8.5%, the approval of the Childhood Cancer Law, improvements in the management of patients with febrile neutropenia, and a reduction in rates of events of clinical deterioration and mortality of hospitalized patients. The Cure *All* implementation framework allows local teams to implement specific strategies and monitor early outcomes in pediatric oncology.

Conclusions. The results obtained reflect the teamwork, the leadership of the authorities, the technical support of professionals, and the support of involved organizations. Further actions will be needed to guarantee sustainability, and monitoring tools are needed to assure success in the planned activities.

Keywords Neoplasms, prevention & control; child health; health programs and plans; health policy; Peru.

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Childhood neoplasms are an important cause of disease burden. According to the Institute for Health Metrics and Evaluation, neoplasms in children under 19 years of age rank fourth in years of life lost due to disability globally, and in Peru it is sixth (1). The burden of childhood cancer can be effectively reduced through public health policies to generate substantial health benefits and prevent millions of unnecessary deaths (2).

Peru is classified as an upper-middle-income country and has a significant youth population, with 10 176 529 people under the age of 19, representing 37% of the total population (3). The estimated incidence rate is 15 cases of childhood cancer per 100 000 population. Data from the Global Cancer Observatory show that, every year, at least 1 559 children and adolescents in Peru between the ages of 0 and 19 years are diagnosed with cancer. The cancer mortality rate is 6.7 per 100 000 population, higher than the regional average and significantly higher than that of developed countries. The most prevalent neoplasm is leukemia, with 40.6% of cases, followed by central nervous system tumors (12.1%) and non-Hodgkin lymphoma (7.6%) (4).

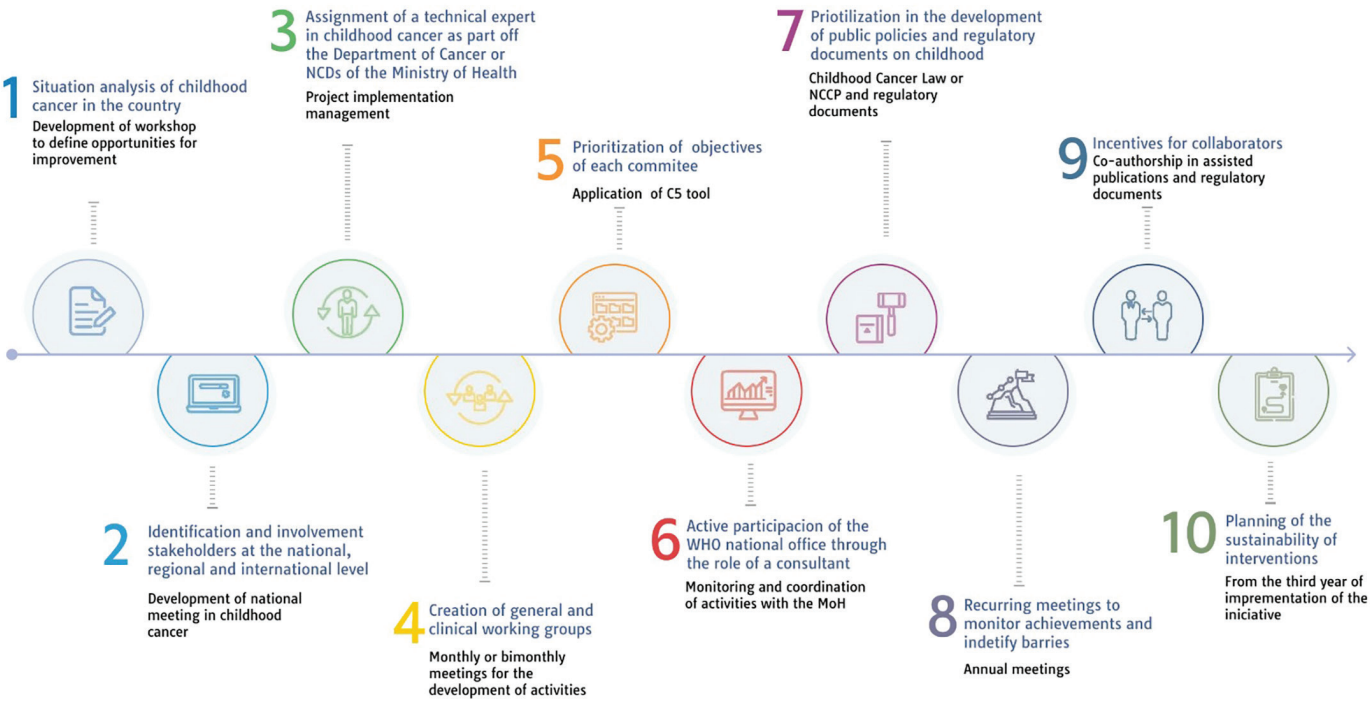
The Metropolitan Lima Cancer Registry (2013–2015) (5) indicates that the overall five-year survival for all types of cancer in children under 19 years of age is 63.7%; however, this survival is not homogeneous for all neoplasms or for all centers nationwide. Diagnostic delay, abandonment of treatment, and the deficient resolution capacity of the health system are determining factors in the low survival of children and adolescents with cancer in Peru (6–8).

In 2019, Peru was chosen as the first index country to implement the Global Initiative for Childhood Cancer (GICC) launched by the World Health Organization (WHO) in the Americas (9). The Ministry of Health committed to its implementation, organizing several face-to-face and virtual national meetings on childhood cancer to review, discuss, and prioritize childhood cancer activities identified to strengthen care for children and adolescents with cancer, as well as the implementation of a national plan against childhood cancer (10).

The WHO GICC was announced in September 2018 with the goal to reduce the suffering of children with cancer and achieve a cancer survival rate of at least 60% by the year 2030. Concerted efforts are now being made at the global, regional, and national levels, based on the implementation a package of strategic technical interventions within the WHO Cure*All* framework (9, 11).

The framework consists of four pillars of action, which, along with its three enablers, form the acronym **Cure*All***: **C**entres of excellence and care networks with a sufficient and competent workforce to increase capacity to deliver quality patient-centered services; **U**niversal health coverage by integrating childhood cancer as part of the full range of essential quality-assured services and included in benefit packages; **R**egimens and roadmaps for diagnosis and treatment that are context-appropriate and facilitate delivery of quality services through evidence-based utilization of essential health products; **E**valuation and monitoring, with robust information systems and research to ensure effective implementation, coupled with research on the unique genetic, epigenetic, environmental,

FIGURE 1. Framework for the implementation of the Global Initiative for Childhood Cancer in Peru



Source: Prepared by Claudia Pascual Morales M.D., Pan American Health Organization, Lima, Peru, 2023.

and societal aspects of childhood cancer in different populations (11). The three Cure*All* framework enablers—**A**dvocacy; **L**everaged financing; **L**inked governance—together support coherent comprehensive policies, and access and coverage of quality health services and systems (11). The GICC focuses on six cancers: acute lymphoblastic leukemia, Burkitt lymphoma, Hodgkin lymphoma, retinoblastoma, Wilms tumor, and low-grade glioma (9, 11).

This article presents the results of participatory evaluation conducted with stakeholders from several governmental institutions, nonprofit organizations, and international partners, led by the Department of Cancer Prevention and Control (DPCAN) of the Ministry of Health. It highlights several key processes for the implementation of the Cure*All* initiative in Peru, which are also relevant to other countries with similar contexts. A reference framework for implementing Cure*All* is presented in Figure 1, which enables local teams to implement specific strategies and monitor early results in pediatric oncology.

The objective of this article is to report the progress of WHO GICC implementation using the *CureAll* framework in Peru, which can be replicated in low- and middle-income countries.

MATERIALS AND METHODS

To carry out this study, a mixed method was used consisting of participatory and documentary evaluation. The participatory evaluation included stakeholders from various government institutions, nonprofit organizations, and international partners, and was led by the Department of Cancer Prevention and Control (DPCAN) of the Ministry of Health. The documentary aspect consisted of the review of data on the regulatory environment, national projects, and interventions implemented since the launch of the GICC in Peru.

The Ministry of Health assigned DPCAN to oversee the implementation of the GICC, with technical support from the Pan American Health Organization (PAHO), St. Jude Children's Research Hospital (St. Jude), and collaboration from various national and international stakeholders, including the National Institute of Neoplastic Diseases (INEN), Social Security of Peru (ESSALUD), the International Society of Paediatric Oncology (SIOP), health professionals, nongovernmental organizations, universities, scientific associations, civil society, and the private sector.

During 2019 and 2022, DPCAN engaged more than 150 participants in eight working committees (epidemiological surveillance, nursing, supportive care/infections, service delivery, awareness and social support, psychosocial and palliative support, radiology, and surgery) and six clinical committees for the six cancer types prioritized by the GICC (acute lymphoblastic leukemia, Burkitt lymphoma, Hodgkin lymphoma, retinoblastoma, Wilms tumor, and low-grade glioma). These committees have developed several interventions and projects aimed at improving access to and quality of care for children and adolescents with cancer, ranging from the development of policies and regulatory documents to the strengthening of care services.

The implementation of the initiative was based on the Cure*All* framework, with its four pillars of action and three enablers, through a process that followed four coordinated steps: evaluate, plan, implement, and monitor. Each pillar and enabler requires different activities. This implementation strategy makes it possible to identify opportunities for service provision through all levels of the health system.

RESULTS

The results will be presented for each of the Cure*All* components.

Pillar C: Centers of excellence and care networks, with a sufficiently competent workforce

The activities in the implementation of this pillar focused on education and training at all levels of care. Considering the challenges imposed by the COVID-19 pandemic in Peru during 2020 and 2021 and the need to focus on virtual educational interventions, the National School of Public Health (ENSAP) of the Ministry of Health designed a virtual course on early diagnosis of childhood cancer, ultimately training more than 6 000 primary care professionals during 2020 and 2021. Subsequently, in 2022, ENSAP developed a comprehensive pediatric cancer training program including three modules: early detection of childhood cancer, pediatric palliative care, and standards of psychosocial care in childhood cancer (12). Additionally, the new childhood cancer law included an item on an urgent need for universities to incorporate childhood cancer content in the pre- and post-university curriculum in health careers (13). To date, several universities have developed postgraduate courses in pediatric oncology to deepen knowledge in the field. In the nursing field, INEN, the largest referral center for childhood cancer, made efforts to promote training in the implementation of the six SIOP Baseline Standards for Pediatric Oncology Nursing Care in Low- and Middle-Income Countries at a national level (14).

In Peru, childhood cancer care services are located mostly in Lima, the capital, accounting for more than 90% of the treated pediatric cancer cases; therefore, a partial decentralization strategy was needed. The Ministry of Health developed a decentralization plan that included the creation of five new centers: two in Lima and Callao, and two in the regions of La Libertad and Junín (15, 16). Financing for this strategy amid the pandemic represented a great challenge, and the support of nongovernmental organizations and PAHO allowed the opening of three pediatric oncology units.

The decision was made to utilize the St. Jude PrOFILE tool (17) to assess the pediatric hematology–oncology units in five institutions located in Lima and Arequipa, in line with the initiatives identified during the first National Childhood Cancer Meeting in 2019. These institutions completed the Abbreviated PrOFILE tool, and three virtual sessions were held, with 45 participants from various disciplines and institutions, including civil society representatives such as foundations. The primary objective of these sessions was to identify priorities at both the institutional and national levels in the context of the ongoing GICC implementation that could be implemented within three years. Descriptive reports, based on specific scores for each institution and nationally, were generated and shared with each participating institution (18).

The PrOFILE tool generated recommendations that were prioritized at the national level, including the establishment of a hospital-based cancer registry, the development and strengthening of safe chemotherapy guidelines, a reduction in the lag time between initial presentation and diagnosis, and an increase in the number of patients treated with curative intent. These recommendations were proposed to the working committees of

the GICC Peru. The evaluation proved beneficial in determining the situation of each center and allowed for increased availability of beds and the hiring of human resources. Additionally, the evaluation facilitated the development of a nursing standard for guidelines that ensure safe chemotherapy and expedited the process of implementing the cancer registry.

Pillar U: Universal health coverage

A few years ago, the development of policies aimed at universal health coverage for pediatric cancer patients, including universal access to medicines and essential technologies, was limited. However, since June 2019 there has been an increase in the development and approval of national cancer plans and policies in Peru. These plans aim to address the existing gaps in cancer and childhood cancer, marking a significant milestone in public health policies in the country (19, 20).

Interestingly, following the passage of the Childhood Cancer Law in September 2020 (21), a National Cancer Law was also enacted in 2021 that complements aspects related to universal coverage of cancer, as well as financing and social protection (22). These regulations ensure that cancer plans have an approved budget, regulate the use of high-cost drugs, and require the creation of a national oncology network that includes public, private, and mixed-model centers to provide comprehensive cancer care. This care involves timely detection, diagnosis, treatment, and follow-up of cancer patients throughout the country (23).

Pillar R: Regimens and roadmaps for diagnosis and treatment that are context appropriate

This section highlights the work of the clinical committees in developing treatment guidelines for pediatric cancer, including acute leukemia, Burkitt lymphoma, Hodgkin lymphoma, retinoblastoma, Wilms tumor, and brain tumors, as well as a nursing care and pediatric palliative care guide. During the COVID-19 pandemic in Peru, patients in remote areas experienced delays in referrals, diagnosis, and care, as well as challenges accessing palliative care. However, the ONCOpeds application was utilized to maintain contact and follow-up with patients despite the distance, allowing pediatric oncologists to communicate with parents and first-level physicians during the pandemic (24). Telemedicine was encouraged to facilitate telediagnosis and follow-up consultations during the pandemic. As a result, there has been an increase in efficiency in the referral and counter-referral system, which has enabled patients living in remote areas with Internet access to be referred more easily.

Pillar E: Evaluation and monitoring

With the support of St. Jude and PAHO, the Ministry of Health established a hospital-based pediatric cancer registry network in October 2020, initially with the participation of five leading childhood cancer institutions. This network was later expanded to include 11 centers, reporting over 1 500 cases annually (25, 26). The National Center for Epidemiology, Disease Prevention and Control (CDC) of the Ministry of Health adopted this registry and developed a technical health standard for the epidemiological surveillance of cancer, including cancer in children and adolescents, as well as the hospital registry. This standard was recently approved, and the Ministry is currently working on the development of a national cancer registry platform, which includes a childhood cancer registry, and providing training for its implementation at the national level.

Likewise, in order to carry out epidemiological monitoring and surveillance, the National Childhood Cancer Observatory was established, consisting of members from institutions of the Ministry of Health, ESSALUD, and civil society. The main objective of this observatory is to report information on new cases, mortality, and treatment abandonment, which helps to propose actions and monitor progress in the treatment of cancer in children and adolescents. As a next step, the Ministry of Health launched a publicly accessible digital platform called the National Child and Adolescent Cancer Observatory, which is fed with information from the hospital registry (27).

Enablers A, L, and L: Advocacy, Leveraged financing, and Linked governance

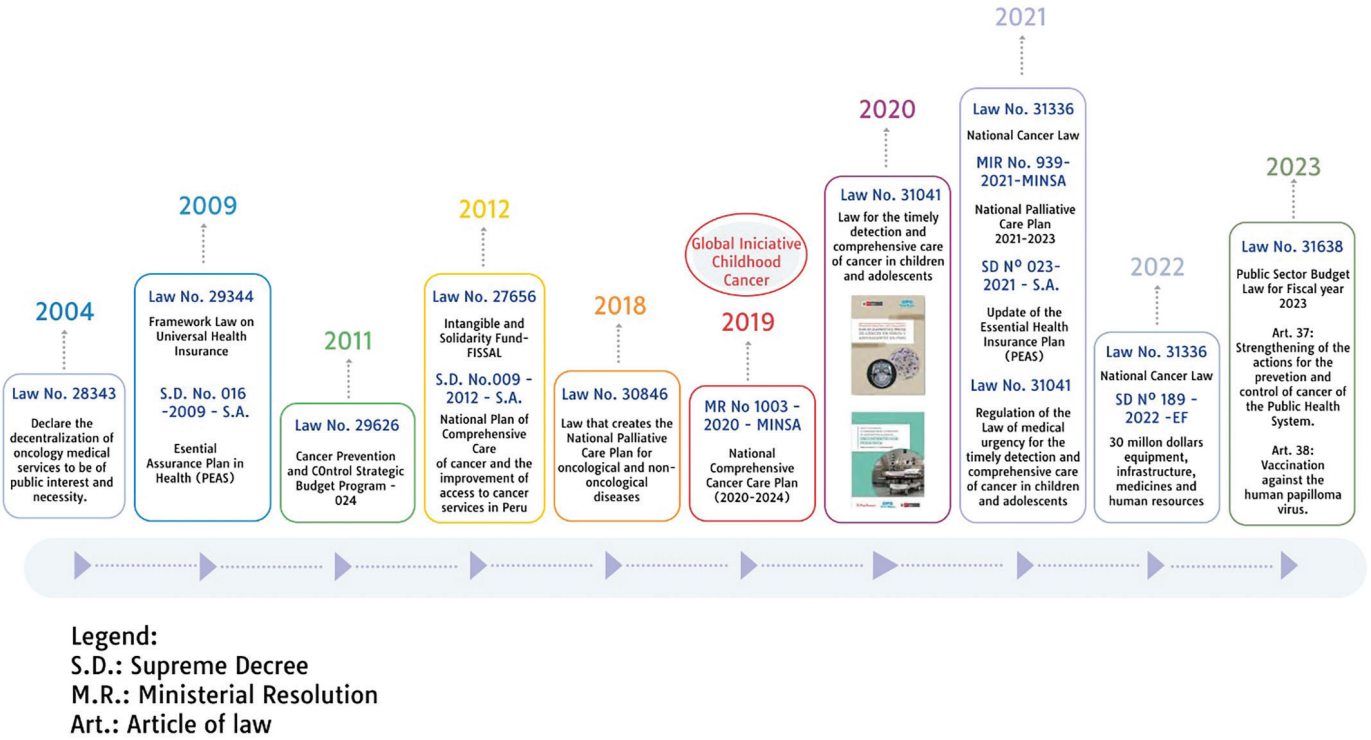
The Ministry of Health has successfully engaged the private sector in the GICC through strategic partnerships such as the framework agreement for interinstitutional cooperation between Latam Airlines Peru and nongovernmental organizations. This has resulted in significant donations of air tickets for children and adolescents undergoing cancer treatment, and their caregivers. Additionally, the Ministry of Economy has approved direct money transfers to finance professional health services and surgical treatment for pediatric cancer patients at the INEN (28). In 2023 the Public Budget Law has increased financing for cancer to over USD 128 million to strengthen prevention and control of cancer, as well as vaccination against human papillomavirus. Plans are also underway to organize the budget for pediatric solid tumor care to request funding through the budget for results program (29).

The development and approval of six regulatory documents, including the Childhood Cancer Law (2020), the National Cancer Law (2021), the National Cancer Control Plan (2019), the National Palliative Care Plan, the health directive for early detection and care of childhood cancer (2020), the health directive on the organization of health services in oncohematology pediatric health (2020), and the update of the Essential Health Insurance Plan, mark a significant turn in public cancer policies in Peru since the launch of the GICC in 2019. These policies aim to address gaps in cancer care and childhood cancer and pave the way for universal coverage of cancer, financing, and social protection (Figure 2).

As examples of successful strategies and using advocacy, the Pediatric Emergency Department of the Edgardo Rebagliati Hospital has managed to reduce the time for the administration of antibiotics to children with febrile neutropenia and improve emergency care in children with childhood cancer (30).

Similarly, the implementation of the EVAT project (Early Warning Assessment Scale), consisting of identifying early detection of signs of clinical deterioration in patients, was implemented at the INEN, the Guillermo Almenara Hospital and Edgardo Rebagliati Hospital of ESSALUD, and the Regional Institute of Neoplastic Diseases of the South, and resulted in a reduction in the rates of events of clinical deterioration and mortality of hospitalized patients (31).

FIGURE 2. Public policies on cancer in Peru: laws, plans, regulations, financing



***Source*:** Prepared by Essy Maradiegue Chirinos M.D., Instituto Nacional de Enfermedades Neoplásicas, Lima, Peru, 2023.

DISCUSSION

Our study analyzes the situation of childhood cancer in Peru characterized by delay in diagnosis, abandonment of treatment, and centralization of health services, and the advances made since the launch of the GICC. A population-based analysis of the association of health system factors with childhood leukemia mortality in Peru described an increase in leukemia mortality in remote centers that have fewer human resources, infrastructure, and equipment (32).

The implementation of the GICC in Peru fostered childhood cancer being considered a public health priority, with the Ministry of Health assuming the commitment and accelerating the improvement process (10); however, the COVID-19 pandemic proved a significant challenge to continuing as planned. At this time, civil society and our external collaborators (PAHO, St. Jude) played an important accompanying role. Nongovernmental and civil organizations financed medicines, medical supplies, lodging, travel, and the implementation of new services.

An important advance is the significant reduction in abandonment of pediatric cancer treatment in Peru since the start of the joint work of the local team, aligned with the Cure*All* framework. The reported treatment dropout rate prior to GICC implementation was 18%, a high rate for an upper-middle-income country like Peru. Abandonment of treatment in childhood cancer has multifactorial causes, among which socioeconomic factors (low level of average family income and low level educational attainment of the parents), cultural factors (refusal of treatment due to the association of cancer with "incurability" and mystical beliefs), and geographical factors (long distances from place of residence to the care center) are the factors most associated with this problem. A multisectoral national strategy adopted by the Ministry of Health, INEN, and several public hospitals—which consists of forming local committees of specialists to prevent abandonment; using an application to monitor cases remotely; engaging a liaison monitor for families, and coordinating with social assistance services (a navigator or "accompaniment" program); and active participation of local foundations—was key to reducing the dropout rate from 18.6% to 8.5% (32). However, this rate is still high, mainly due to the socioeconomic limitations of the families as the main factor that determines the abandonment of treatment in Peru (33).

The approval and subsequent regulation of the Childhood Cancer Law represented a significant milestone for pediatric cancer care in Peru. Making the economic subsidy for families of children with cancer effective is a major challenge, as only 25% of the families of children and adolescents with cancer have parents with a formal job, adding to the urgent need for financing availability that affects most families. A national study in Peru on out-of-pocket expenses (34) or direct payments among parents/caregivers of children and adolescents with cancer revealed that the expense incurred by each family when a child is diagnosed with cancer exceeds the capacity of most families to pay (86% of family income before final diagnosis and 75% after cancer diagnosis); this means a catastrophic expense for these families before and after the diagnosis. Most of the out-of-pocket expenditure items were not covered by their insurance, as well as the fees charged for medical care,

medicines, transportation, food, lodging, and others. Based on this study, to provide financial relief and help reduce the rate of dropout from treatment, the Ministry of Health proposed the modification of the economic subsidy to allow granting a subsidy to 65% of the families that are in a situation of poverty and extreme poverty.

Our study has some limitations. Despite the fact that the study used a mixed method of participatory evaluation including different actors and a documentary review, it is possible that it has research biases, with optimistic results, and for this reason we tried to use indicators and carry out an exhaustive search for information. Likewise, we consider it necessary to have follow-up metrics or indicators based on the hospital registry and/or population base, and indicators of the initiative's processes that can be developed according to the areas of opportunity for improvement identified in each country.

In conclusion, this study shows that the implementation of the WHO GICC is possible and can be replicated in countries with similar contexts. The achievements obtained in Peru result from teamwork, leadership of the authorities, technical support of professionals, and the involvement of the supporting organizations St. Jude and PAHO, which has been vital for success. Further actions will be needed to guarantee sustainability, and monitoring tools are needed to assure success in the planned activities.

Author contributions. EM, CP, and LV designed the study, interpreted the data, critically reviewed the findings, and drafted the manuscript. All authors engaged in the analysis. All authors reviewed and approved the final version of the manuscript.

Conflict of interest. None declared.

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Manuscript submitted on 2 April 2023. Revised version accepted for publication on 5 July 2023.

Fortalecimiento de las políticas de salud pública contra el cáncer infantil: logros de Perú en el marco de la Iniciativa Mundial de la OMS contra el Cáncer Infantil

RESUMEN

Objetivo. Informar sobre los avances de Perú en el periodo transcurrido a partir de junio del 2019, en relación con la puesta en práctica de la Iniciativa Global de la Organización Mundial de la Salud contra el Cáncer Infantil utilizando el marco CureAll, que es posible replicar en los países de ingresos bajos y medianos.
Métodos. Se utilizó un método mixto de evaluación participativa y documental. En la evaluación participativa intervinieron las partes interesadas de diversas instituciones gubernamentales, organizaciones sin fines de lucro y asociados internacionales. El aspecto documental consistió en un examen de los datos sobre el entorno regulatorio, los proyectos nacionales y las intervenciones llevadas a cabo. El Ministerio de Salud involucró a más de 150 participantes que formaron los comités de trabajo que han elaborado documentos normativos y regulatorios a fin de reforzar los servicios de asistencia.
Resultados. Entre los logros cabe citar la disminución del 18,6% al 8,5% de la tasa nacional de abandono del tratamiento, la aprobación de la Ley de Cáncer Infantil, las mejoras en el tratamiento de los pacientes con neutropenia febril y la reducción de las tasas de episodios de deterioro clínico y de mortalidad en los pacientes hospitalizados. El marco de aplicación de CureAll permite que los equipos locales pongan en práctica estrategias específicas y realicen un seguimiento de los resultados iniciales en el ámbito de la oncología pediátrica.
Conclusiones. Los resultados obtenidos reflejan el trabajo en equipo, el liderazgo de las autoridades, el respaldo técnico de los profesionales y el apoyo de las organizaciones implicadas. En el futuro, será necesario adoptar nuevas medidas para asegurar su viabilidad, y será preciso contar con herramientas de seguimiento para garantizar el éxito de las actividades planificadas.

Palabras clave Neoplasias, prevención & control; salud infantil; planes y programas de salud; política de salud; Perú.

Fortalecimento das políticas públicas de saúde para o câncer infantil: As conquistas do Peru por meio da Iniciativa Global da OMS para o Câncer Infantil

RESUMO

Objetivo. Relatar o progresso, desde junho de 2019, da implementação da Iniciativa Global da Organização Mundial da Saúde para o Câncer Infantil no Peru, no âmbito do marco Cure*All*, que pode ser replicado em países de baixa e média renda.
Método. Foi utilizado um método misto de avaliação participativa e documental. A avaliação participativa incluiu interessados diretos de diferentes instituições governamentais, organizações sem fins lucrativos e parceiros internacionais. O aspecto documental consistiu em uma revisão de dados sobre o ambiente regulatório, projetos nacionais e intervenções implementadas. O Ministério da Saúde do Peru contou com mais de 150 participantes para a formação de comitês de trabalho, que elaboraram políticas e documentos normativos para fortalecer os serviços de atenção primária à saúde.
Resultados. Entre os resultados alcançados estão a redução da taxa nacional de abandono do tratamento, de 18,6% para 8,5%, a aprovação da Lei do Câncer Infantil, melhorias no manejo de pacientes com neutropenia febril e redução nas taxas de deterioração clínica e mortalidade de pacientes hospitalizados. A implementação do Cure*All* permite que as equipes locais adotem estratégias específicas e monitorem os resultados iniciais em oncologia pediátrica.
Conclusões. Os resultados obtidos refletem o trabalho em equipe, a liderança das autoridades, o suporte técnico dos profissionais e o apoio das organizações envolvidas. Serão necessárias mais ações para garantir a sustentabilidade, além de ferramentas de monitoramento para assegurar o sucesso das atividades planejadas.

Palavras-chave Neoplasias, prevenção & controle; saúde da criança; planos e programas de saúde; política de saúde; Peru.