

# National Strategic Plan on Childhood & Adolescent Cancer Care in Sri Lanka 2021-2025



**National Cancer Control Programme**  
**Ministry of Health**  
Sri Lanka



# **National Strategic Plan on Childhood and Adolescent Cancer Care in Sri Lanka (2021 – 2025)**



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## Message from the Director General of Health Services



It is with great pleasure that I send this message to the 'National Strategic Plan on Childhood and Adolescent Cancer Care in Sri Lanka 2021-2025'. This will be the first five-year plan for the 'Global Initiative for Childhood Cancer' (GICC) of World Health Organization towards achieving at least 60% survival for childhood cancers in the year 2030 and reducing the suffering of the affected child and the whole family. Being a focus country for the Global Initiative for Childhood Cancer, developing first 5 year plan will guide all stakeholders to work in coordinated manner. This strategic plan will be an extension of National Strategic Plan on Prevention and Control of Cancer in Sri Lanka 2020-2024.

The partnership of different stakeholders including Ministry of Health Officials, Professional Colleges, Clinicians and other health care staff, Development Partners, Civil Society Organizations facilitated in developing 'National Strategic Plan on Childhood and Adolescent Cancer Care in Sri Lanka 2021-2025'. Their contributions are highly appreciated. Also, it is expected that active participation of all stakeholders will be available to complete the identified major activities with in the stipulated time period.

Finally, the coordination and hard work of National Cancer Control Programme and the Technical partnership of WHO Country office is highly appreciated.

**Dr. Asela Gunawardena**

Director General of Health Services



## Message from the Deputy Director General Non - Communicable Diseases



I am happy to send this message to the 'National Strategic Plan on Childhood and Adolescent Cancer Care in Sri Lanka 2021-2025'. Development of this strategic plan will be a major national response to the Global Initiative of Childhood Cancer (GICC) of World Health Organization. Also, it will further strengthen the ongoing implementation of National Strategic Plan on Prevention and control of Cancers in Sri Lanka 2021-2025.

The National Strategic Plan on Childhood and Adolescent Cancer Care will serve as the main guiding document for Sri Lanka to achieve the targets proposed by the global initiative including achievement of at least 60% survival of childhood cancers and improving the quality of life of both the affected child and the rest of the family. This ensures that the affected children and adolescents receive care they need without suffering financial hardships, with coverage of full spectrum of essential quality health services in the fields of early diagnosis, treatment, rehabilitation, survivorship and palliative care.

I acknowledge the active participation of all stakeholders for their contributions and World Health Organization for the technical partnership. The facilitator role of National Cancer Control Programme is highly appreciated. On behalf of Ministry of Health, we look forward to work with all the government institutions, developmental partners, private sector and civil society stakeholders to complete the proposed tasks of this strategic plan.

**Dr. Champika Wickramasingha**  
MBBS, MSc, MD (Community Medicine)  
Deputy Director General (Non-Communicable diseases)  
Ministry of Health





## Message from the World Health Organization Representative to Sri Lanka



Cancer is a leading cause of death for children and adolescents, particularly in high-income countries. The likelihood of surviving a diagnosis of childhood cancer depends on the country in which the child lives: in high-income countries, more than 80% of children with cancer are cured, but in many low and middle income countries only 15-45% are cured. The reasons for lower survival rates include: delay in diagnosis and advanced disease, an inability to obtain an accurate diagnosis, inaccessible therapy, abandonment of treatment, death from toxicity and side effects, and avoidable relapse. Improving access to childhood cancer care, including to essential medicines and technologies, is highly cost effective, feasible and can improve survival in all settings

In this background, in 2018, WHO launched, together with partners, the Global Initiative for Childhood Cancer (GICC), to provide leadership and technical assistance to governments to support them in building and sustaining high-quality childhood cancer programmes. The goal is to achieve at least 60% survival for all children with cancer and reduce suffering, globally, by 2030. This represents an approximate doubling of the current cure rate and will save an additional one million lives over the next decade. The objectives of the Initiative are to increase capacity of countries to deliver best practices in childhood cancer care and to Increase prioritization of childhood cancer at the global, regional and national levels.

I am particularly pleased that Sri Lanka is one of the countries supported by the GICC. The National Strategic Plan on Childhood and Adolescent Cancer Care in Sri Lanka (2021 – 2025) will serve as the main guiding document for strengthening childhood cancer care linking all national and international stakeholders in Sri Lanka. WHO is looking forward to the continuing partnership with Government of Sri Lanka and other key stakeholders to implement the national strategic plan.

**Dr. Alaka Singh**

World Health Organization Representative to Sri Lanka



## Message from the Director National Cancer Control Programme



I am pleased to present the 'National Strategic Plan for Childhood and Adolescent Cancer Care for Sri Lanka 2021- 2025'. This will be a guiding document for Sri Lanka's response to childhood and adolescent cancer care in the next five years with identified targets in the fields of early diagnosis, management and survivorship care for children and adolescent with cancers. Upgrading early diagnosis and treatment facilities will lead to improve the survival and quality of life of cancer patients and their families. The strategies address on acceleration of national response, ensure timely and accurately diagnosis, improve comprehensive cost-effective treatment, ensure access to rehabilitation, long term survivorship care and community reintegration, ensure access to palliative care services, strengthen the management information and promote research and utilization of its findings.

This National Strategic Plan will give strategic directions to both government and non-government sectors. The proposed interventions will be targeted to children living with cancers and their families in coordinated and unified approach. It is expected from all relevant stakeholders to utilize this document to ensure optimum service provision for children and adolescents with cancers including survivorship care and palliative care.

The National Cancer Control Programme sincerely appreciates the commitments of those who contributed to complete this task. The technical partnership from the World Health Organization to the National Cancer Control Programme for this endeavor is gratefully acknowledged.

**Dr. Janaki Vidanapathirana**

MBBS, MSc, MD (Community Medicine)

Director, National Cancer Control Programme



## Acknowledgement

The task of developing the National Strategic Plan on Childhood and Adolescent Cancer Care in Sri Lanka 2021-2025 could be completed despite the challenges posed by the Covid 19 pandemic due to the dedicated support of all the stakeholders and the team at the National Cancer Control Programme and the National Cancer Institute, Sri Lanka (NCISL)

The leadership and administrative guidance of Dr. Sanjeewa Munasingha (Secretary - Health and Chairperson of National Advisory Committee on Prevention and Control of Cancers), Dr. Lakshmi Somatunga (Additional Secretary – Public Health Services), Dr. Sunil De Alwis (Additional Secretary – Medical Services) and Dr. Asela Gunawardena (Director General of Health Services) were immensely helpful in completing this task. Dr. Champika Wickramasingha (DDG-NCD) was a pillar of strength in this task providing regular guidance and support. Continuous encouragement of Dr. Janaki Vidanapathirana (Director, National Cancer Control Programme) to complete the task in time needs to be mentioned with gratitude.

The core group comprising Dr. Champika Wickramasingha (DDG-NCD), Dr. Janaki Vidanapathirana (Director, NCCP), Dr. Priyantha Wijesinghe (Acting Deputy Director, NCCP), Dr. Sanjeeva Gunasekera (Consultant Paediatric Oncologist), Dr. Mahendra Somathilaka (Consultant Paediatric Oncologist), Dr. Wasantha Rathnayaka (Consultant Oncologist with Special Interest in Paediatric Oncology), Dr. Thushari Hapuarachchi (Consultant Oncologist with Special Interest in Paediatric Oncology), Dr. Rukmal Gunathilaka (Consultant Paediatrician – NCISL), Dr. Suraj Perera (Consultant Community Physician, NCCP), Dr. Irosha Nilaweera (Consultant Community Physician, NCCP), Dr. Muzrif Munas (Consultant Community Physician, NCCP), Dr. Upuli Perera (Consultant Community Physician, NCCP), Dr. Nalika Gunawardena (NPO-NCD, WHO Country office), Dr. D.M.S. Manori (Senior Registrar in Community Medicine) and Dr. Nirma Alapitiarachchi (Registrar in Community Medicine) worked tirelessly contributing, drafting, revising and adding the final touches to the National Strategic Plan on Childhood and Adolescent Cancer Care in Sri Lanka 2021-2025. The suggestions provided by Dr. Vijith Gunasekera (Director), Dr. Lalith Poddalgoda (Deputy Director) and senior staff of National Cancer Institute, Dr. G. Wijesuriya (Director) and Senior Staff of Lady Ridgeway Hospital for Children are highly appreciated. The regular updates from GICC initiative received from Dr. Sanjeeva Gunasekera (Country focal point for Childhood Cancer Network of WHO SEARO) was greatly helpful in aligning the strategic plan with ongoing global initiatives.

The observations received from all DDGs, Directors and other senior staff of Ministry of Health were extremely beneficial for improving the National Strategic Plan. The suggestions of Professional Colleges and Associations (Sri Lanka Medical Association, Sri Lanka College of Oncologists, Sri Lanka College of Paediatricians, College of Pathologists of Sri Lanka, Sri Lanka College of Haematologists, Sri Lanka Association of Clinical Pharmacology and Therapeutics, Sri Lanka College of General Practitioners, Sri Lanka College of Community Physicians, Sri Lanka College of Chemical Pathologists, Sri Lanka College of Radiologists, Sri Lanka College of

Microbiologists ) , Consultants and other experts, Academia, Development Partners (including WHO, World Bank, UNICEF, UNFPA), Non-Governmental Organizations and Civil Society Organizations went a long way in developing this comprehensive National Strategic Plan. In addition, Senior Registrars of MD Community Medicine 2021/2022 batch critically evaluated and gave valuable inputs to improve this publication. The inputs received from Dr. Damayanthi Pieris (Senior Consultant Oncologist), Dr. Kanthi Perera (Consultant Oncologist), Dr. B.J.C. Perera (Senior Consultant Paediatrician), Dr.Eshani Fernando (Director -Planning) was also helpful in finalizing the document.

WHO Country office worked closely giving unstinted support to complete this task within the stipulated timeline. The dedicated role played by Dr. Nalika Gunawardena (NPO- NCD WHO Country Office) needs special mention. The technical guidance of Dr. Alaka Singh (WHO Country Representative), Dr. Razia Pendse (Former WHO Country Representative) and Dr. Olivia Niveras (Public Health Administrator WHO Country Office) is greatly valued. The continuous motivation and advice of Dr. Dorji Gampo (Technical Officer – WHO SEARO) and Dr. Bishnu Rathnagiri (GICC Coordinator, WHO SEARO) is also greatly appreciated.

With the NCISL joining the St Jude Global Alliance, Sri Lanka was invited to pilot the Country Collaboration for Childhood Cancer or the C5 tool, and inputs received during this process from the Health Systems unit of the Global Paediatric Medicine Department of the St Jude Children's Research Hospital led by Dr. Catherine Lam also played a significant role in developing the final product.

The task was coordinated by the Strategic Information Management Unit of NCCP despite significant work pressures with the contributions of Dr. D.M.S. Manori, Dr. Nirma Alapitiarachchi, Dr. Chathurika Jayamani, Dr. Nirmala Jayanthi, Dr. Ahamed Ziyad, Dr. Novandi Samarasingha and PHNS Chamila Nilakshi. The extended support of whole NCCP team is greatly appreciated.

The cover page of the book was designed by Mr.Thasitha Sandaruwan (former PHI-NCCP) and printing was done by MS Solutions (Pvt ) Ltd.

While appreciating the contributions of everyone in developing this strategic plan, in the same spirit it is expected that all everyone will join together to implement the strategic plan with the ultimate goal of improving outcomes of childhood and adolescent cancers in Sri Lanka and improving the quality of life of the affected children and their family.

**Dr. Suraj Perera**

Consultant Community Physician  
Strategic Information Management Unit  
National Cancer Control Programme

## Abbreviations

<b>ASR</b>	Age Standardized Rate
<b>CCN</b>	Childhood Cancer Care Network
<b>CoE</b>	Center of Excellence
<b>GICC</b>	Global Initiative on Childhood Cancer
<b>IAEA</b>	International Atomic Energy Agency
<b>IARC</b>	International Agency for Research on Cancer
<b>ICCC-3</b>	International Classification of Childhood Cancer, Third edition
<b>LMIC</b>	Low and Middle Income Countries
<b>MDT</b>	Multi-Disciplinary Team
<b>MRD</b>	Minimal Residual Disease
<b>MSD</b>	Medical Supplies Division
<b>NAC</b>	National Advisory Committee
<b>NCISL</b>	National Cancer Institute of Sri Lanka
<b>NEML</b>	National Essential Medicine List
<b>NMRA</b>	National Medicines Regulatory Authority
<b>NTS</b>	Nurses Training School
<b>OPE</b>	Out of Pocket Expenditure
<b>PACS</b>	Picture Archiving and Communication System
<b>PET-CT</b>	Positron Emission Tomography - Computed Tomography
<b>PEWS</b>	Paediatric Early Warning Score
<b>SIOP</b>	International Society of Pediatric Oncology
<b>SJGA</b>	St. Jude Global Alliance
<b>SOP</b>	Standard Operating Procedure
<b>TAC</b>	Technical Advisory Committee
<b>TOR</b>	Terms of Reference





## Executive Summary

Cancers detected from birth up to completion of 19 years (0-19) are considered as 'Childhood Cancers'. To give the emphasis that adolescent age groups are also included, it is also named as 'Childhood and Adolescent Cancers'. Even though the burden of childhood cancer is relatively less than adult cancers, there is a rising trend in cancers among children and adolescents. Also, childhood cancer has become one of the leading cause of death among children universally specially among developing countries.

During 2015-2019 time period, on average about 828 childhood cancers were detected per year in Sri Lanka. Overall male: female ratio of incidence of childhood cancer was nearly 1:1 (eg: 2019 male - 402, female - 378). The age standardized incidence rate of childhood cancers increased from 73.1 per 1,000,000 population (male – 74.5, female 71.6) in year 2005 to 108.4 per 1,000,000 (male -111.5, female -105.1) in year 2019. According to the hospital based cancer registry of National Cancer Institute, Sri Lanka in year 2020, Leukaemia (51%), Bone tumours (11%), Lymphomas (10%), CNS and brain tumours (9%) were the commonest cancers among males while Leukaemia (41%), Germ cell tumours (11%) and CNS and brain tumours (11%) were the commonest cancers among females.

During 2010-2014 time period, total number of childhood cancer deaths in Sri Lanka was considered, on average about 263 deaths per year occurred according to the data from the civil registration system in Sri Lanka. Overall male: female ratio of mortality of childhood cancer was nearly 1.2:1 (in 2014 male - 150, female - 119). The age standardized mortality rate of childhood cancers increased from 36.8 per 1,000,000 population (male – 40.0, female -33.4) in year 2010 to 38.6 per 1,000,000 (male -42.7, female -34.5) in year 2014. Highest number of deaths due to childhood cancers occurred due to Leukemias (On average 37 %cancer deaths among males & 28% cancer deaths among females per year ) and Brain & central nervous system tumours (on average 15% cancer deaths among males & 19% cancer deaths among females per year).

The process of developing the strategic plan included a detailed situation analysis and review of published documents including National Policy on Prevention and Control of Cancers (2015), IAEA/WHO impact review recommendations, similar strategic plans in other settings and the directives of WHO Global Initiative of Childhood Cancer. Core group was identified and initial draft was developed. Through series of stakeholder consultations and a national consultation, key strategic objectives and major activities were finalized.

National Strategic Plan on Childhood and Adolescent Cancer Care 2021-2025 is based on several guiding principles, such as high level of political commitment, ensuring human rights, protecting equity and social justice, adhering to Universal Health Coverage, facilitating multisectoral coordinated approach and empowering community and family for cancer care.

The National Strategic Plan is aligned with National Health Policy 2016-2025 and National Strategic Plan on Prevention & Control of Cancers for year 2020-2024. It is also aligned with the Global Initiative on Childhood Cancer which was launched in year 2018. Sri Lanka is aiming to achieve highest possible survival rate, while reducing suffering and improving quality of life in children with cancer.

This National Strategic Plan on Childhood and Adolescent Cancer Care gives priority to develop integrated national programme with leadership, advocacy and governance. Strengthening early diagnosis and prompt treatment of affected children with cancers and improving the quality of life of affected children and their families are key priorities. It includes several strategies to ensure timely and accurate diagnosis, to improve comprehensive cost-effective treatment options, to ensure rehabilitation, long term survivorship care and community reintegration, to ensure access to palliative care services, to strengthen the Information Management Systems and to promote research related to childhood adolescent cancers to optimize the care and the wellbeing of affected children and families.

The strong collaboration among key stakeholders within the Ministry Health including National Cancer Institute Sri Lanka and other relevant cancer treatment centres, Lady Ridgeway Hospital for Children, Sirimavo Bandaranaike Specialized Children Hospital and other hospital network, National Cancer Control Programme and other preventive health institutions, professional colleges, civil society organizations, Ministry of Education and other non-health government institutes, development partners are essential to implement the proposed activities adhering to set timeline.

A monitoring and evaluation plan with a results framework will be used to monitor and evaluate programme performance.

The present national strategic plan which was developed, through strong stakeholder participation will be used as an overarching framework to guide and coordinate activities in a systematic manner to provide comprehensive childhood and adolescent cancer care in Sri Lanka.

The experience in developing, implementing and monitoring the current strategic plan, will lay the foundation for more robust and effective strategic plans in the future.

# **National Strategic Plan on Childhood & Adolescent Cancer Care in Sri Lanka: 2021-2025**

## **Introduction**

Developing a National Strategic Plan on Childhood & Adolescent Cancer Care is essential as it will identify relevant key activity areas for the improvement of Childhood & Adolescent Cancer Care in the next five years. This 5 year plan was developed through the evidence synthesis and stakeholder consultation.

Cancer is uncontrolled abnormal proliferation of cells in any organ of the body. The most common cancers among children and adolescents (0-19 yrs) are leukaemias, lymphomas, tumours arising in the central nervous system, kidneys and bones (1).

Even though the burden of childhood cancer is relatively less compared to adult cancers, there is a rising trend in cancers among children and adolescents. Cancer burden is specially felt in Low and Middle Income Countries (LMICs) where vast majority of the world's childhood cancer incidence occurs (3).

Unlike adult cancers, the aetiology of most childhood cancers remain unclear. However, cancers like leukaemia can have genetic and environmental predisposing factors. For instance, ionizing radiation exposure, chemicals like benzene and pesticides are some of the environmental risk factors, while children with Fanconi's anaemia, Wiskott-Aldrich syndrome, Down syndrome, Bloom's syndrome are at higher risk of developing cancer (2).

Fortunately, most of the childhood cancers can be cured using commonly available treatment modalities. In developed countries, childhood cancer cure rates often exceed 80% while in LMICs it can be as low as 20% (3).

## **Global Situation**

Even though incidence of childhood cancer is rare compared to adult cancer, it has become one of the leading causes of death among children globally (4). Annually, about 400,000 children and adolescents are diagnosed with cancer while 284,649 of them are children less than 14 years of age and 100,860 are aged 15- 19 years of age. According to the International Agency for Research on Cancer (IARC), the age standardized rate (ASR) among children less than 14 years is 140.6 per million and the ASR for children aged 15 to 19 years, it is 185.3 per million (5).

The Lancet Oncology commission on childhood cancers estimated that from 2015 to 2030 the number of children with cancer would be increased from 6 million to 7 million cases globally. WHO states that children with cancer in developing countries have a four-fold increase in the

risk of dying than children in developed countries due to the delay in diagnosis and inadequate treatment facilities (6).

In the 2017, World Health Assembly identified that childhood cancer is a public health priority and proposed immediate course of action to counteract the situation. As a result, WHO summoned the first consultation on childhood cancer in Geneva in 2018 and organized the Global Initiative on Childhood Cancer. The goal of the initiative is to reach at least 60% survival rate for children with 6 index cancers by 2030 while reduce suffering in most. It is estimated that this can save an additional one million lives (7). To attain this goal, it was recommended to increase the capacity of all countries to facilitate safe and quality care for children with cancer. WHO with the collaboration of some identified stakeholders such as the International Society of Pediatric Oncology (SIOP) and St. Jude Children`s Research Hospital, USA has launched initiatives to accomplish these objectives.

### **Sri Lankan Situation**

The childhood cancer burden is increasing globally as well as locally. According to the latest available data in 2019, 31,848 new cancer cases have been detected within the year and 780 cases are within the age group of 0-19, making it 2.4% of all cancers. Among all childhood cancer cases reported in the year 2019 in Sri Lanka, 51.5% are males while 48.5% are females. According to the National Cancer Registry Sri Lanka, an average of 828 childhood cancers have been detected per year during 2015-2019 time period. There is an increasing trend in age standardized incidence rate of childhood cancers from 73.1 per million population in 2005 to 108.4 per million population in 2019 (8).

As per the National Cancer Registry 2019 data, leukaemias and myeloproliferative diseases, as a group occupies the first place accounting for 22.0% (n=172) followed by other malignant epithelial neoplasms (14.1%, n = 110), central nervous system neoplasms (10.5%, n=82), soft tissue and other extra-osseous sarcomas (10.4%, n= 81), lymphomas and reticuloendothelial neoplasms (9.1%, n= 71), malignant bone tumours (7.3%, n= 57) , germ cell tumours, trophoblastic tumours, and neoplasms of gonads (5.3%), n= 41, other and unspecified (5.1%, n=40), renal tumours (4.1%, n=32), neuroblastoma (4.0%, n= 31), retinoblastoma (3.7%, n=29) and Hepatic tumours(1.7%, n=13).

Even though there is no explicit evidence on survival rates in childhood cancer in Sri Lanka, it is presumed for selected cancers such as Wilms tumour, Acute Lymphoblastic Leukaemia Germ cell Tumour etc. survival rates are more than 60% according to anecdotal evidence.

## Methodology

Developing National Strategic Plan on Childhood and Adolescent Cancer Care for 2021-2025 was identified as one of the major activities under the Global Initiative of Childhood Cancer (GICC) for Sri Lanka within the WHO Biennium 2020/2021. A National Strategic Plan on Childhood and Adolescent Cancer Care for 2021-2025 is essential, as it will identify relevant key activity areas for childhood and adolescent cancer care needed to improve the outcome in the next five years.

Initially a core group representing members from Ministry of Health, National Cancer Control Programme, National Cancer Institute of Sri Lanka and WHO Country Office brainstormed to identify key strategies.

The existing strategies and major activities in relation to Paediatric cancer care were reviewed. Some of those activities and documents are mentioned below.

- National Policy and Strategic Framework on Cancer Prevention & Control – Sri Lanka launched in the year 2015. It has identified the importance of strengthening interventions for childhood cancer care.

**Policy Objective 3 :** Ensure equitable and continuous accessibility to diagnosis and treatment facilities for cancers.

**Strategy 3.6:** Childhood Oncology services will be improved with the use of affordable and effective standard protocols, paying particular attention to completion of treatment.

- The report of impact review of IAEA/WHO conducted in year 2019 in Sri Lanka for cancer control capacity and needs assessment recommended the following interventions for strengthening childhood cancer care services in Sri Lanka.

### Short to medium-term (6 to 36 months)

- Collaborate with the International Society of Paediatric Oncology (SIOP), WHO and IAEA for training of Paediatric Oncologists and review of their current formal education programme
  - Provide more positions for Paediatric Oncologists in the public hospitals
  - Develop a comprehensive long-term Paediatric cancer policy
  - Establish Paediatric Oncology centres in other main cities, preferably in Jaffna and Kandy.
- 
- National Strategic Plan on Prevention and Control of Cancers in Sri Lanka 2020-2024 has identified major activities for strengthening childhood cancer care in Sri Lanka

**Strategic Direction 4.5:** Improve accessibility and availability of cost-effective evidence based Paediatric Oncology services

**Major Activities**

4.5.1 Scale up Paediatric Oncology services to all Centres of Excellence (CoE) in a phased manner

4.5.2 Ensure comprehensive care for Paediatric cancer patients are provided in the CoEs

4.5.3 Ensure National Essential Paediatric Oncology drugs are available without stockout situations

4.5.4 Establish telemedicine services for Paediatric oncology

Also published strategic plans on childhood cancers in other countries (eg: Australia) and other agencies (eg: SIOP) were reviewed.

After the review of above documents, an initial draft was first prepared and this was further improved following a series of small group discussions.

Then a series of consultative meetings were conducted to obtain observations and inputs from the Director and senior staff of National Cancer Institute, Sri Lanka and Lady Ridgeway Hospital for Children. The revised draft was circulated among academic and professional bodies including Sri Lanka Medical Association, Sri Lanka College of Oncologists, Sri Lanka College of Paediatricians, College of Pathologists of Sri Lanka, Sri Lanka College of Haematologists, Sri Lanka Association of Clinical Pharmacology and Therapeutics, Sri Lanka College of General Practitioners, Sri Lanka College of Community Physicians, Sri Lanka College of Chemical Pathologists, Sri Lanka College of Radiologists, Sri Lanka College of Microbiologists. Their observations were then incorporated to the working draft after evaluation by the core committee. The technical guidance of WHO Country Office, WHO SEAR office and Health Systems unit of the Global Pediatric Medicine Department of the St. Jude Children's Research Hospital were helpful in further improving the draft strategic plan.

Finally, the national consultation to finalize the draft strategic plan was conducted on 3<sup>rd</sup> August 2021 with the participation of Ministry of Health Officials, Clinicians, Academia, representatives of professional colleges and associations, development partners, civil society organizations etc.. Considering the observations received at this National Consultation, strategic directions and major activities were finalized. Sub activities, activity plan and the results framework were then incorporated to help operationalize the National Strategic Plan for five-year duration.

## Guiding Principles of the National Strategic Plan

- Being consistent with the 'National Health Policy', 'National Policy & Strategic Framework on Prevention and Control of Cancers', 'National Strategic Plan on Prevention and Control of Cancer in Sri Lanka 2020-2024' and other relevant government economic and development policies
- Integrated approach across the life course
- High level political commitment
- Adopting human rights approach
- Protecting and promoting equity and social justice
- Universal Health Coverage
- Multidisciplinary, multi-sectoral coordinated approaches
- Encouraging appropriate public – private partnerships
- Community and family empowerment, ownership and participation

## Sri Lanka is committed to achieve the following globally set targets by 2030

1. By 2030, achieve at least 60% survival for childhood in the 6 index cancers as identified by the WHO (Mentioned below).
2. Reduce suffering of patients and their families due to childhood cancers

To achieve above targets, World Health Organization advises member countries to adhere to 'CUREALL' approach.

It recommends following interventions

**C**entres of excellence and care networks with sufficient competent workforce

**U**niversal health coverage with benefit packages and organizational models for quality services

**R**egimens for management with context-appropriate guidance, essential technologies & medicines

**E**valuation and monitoring with quality assurance and robust information systems

**A**dvocacy

**L**everaged financing

**L**inked policies and governance

WHO has identified six common cancers which are highly curable with proven therapies which as a group, represent 50–60% of all childhood cancers as index cancers to focus on during the GICC.



They are:

- Acute lymphoblastic leukaemia (a blood cancer)
- Burkitt lymphoma (a fast-growing lymph gland cancer)
- Hodgkin lymphoma (a lymph gland cancer)
- Retinoblastoma (a childhood eye cancer)
- Wilms tumor (a childhood kidney cancer)
- Low-grade glioma (a brain cancer)

# **National Strategic Plan on Childhood & Adolescent Cancer Care in Sri Lanka: 2021-2025**

## **Vision**

**A country with high cure and survival rates with good quality of life with minimal disabilities & suffering from effects of childhood & adolescent cancers**

## **Mission**

**To achieve high survival with good quality of life of childhood & adolescents cancer patients and their associates through the provision of appropriate services for definitive diagnosis, curative care and follow up holistic care and accessible continuum of cancer care through an evidence-based approach**

## **Goal**

**To improve high survival rates through timely diagnosis, effective treatment and follow up care through the provision of continuum of care to all childhood & adolescent cancer patients in the country in an equitable manner.**

## **National Strategic Plan on Childhood & Adolescent Cancer Care in Sri Lanka: 2021-2025**

### **Strategic Objectives**

- 1) **Accelerate the national response** for childhood and adolescent cancers in Sri Lanka through an integrated national programme with **leadership, advocacy and governance**
- 2) **Ensure timely and accurate diagnosis** of childhood and adolescent cancers in Sri Lanka
- 3) **Improve comprehensive cost-effective treatment** options for childhood and adolescent cancers including chemotherapy, radiotherapy, surgery and other novel therapeutic modalities.
- 4) **Ensure** access to **rehabilitation, long-term survivorship care and community reintegration** of patients with childhood and adolescent cancers
- 5) **Ensure** access to **palliative care services** to meet the needs of patients with childhood and adolescent cancers and their families
- 6) **Strengthen** the **management information system** including cancer registries and comprehensive medical records to monitor the progress and evaluate the outcomes of childhood and adolescent cancers.
- 7) **Promote research** related to childhood and adolescent cancers and **utilization of its findings** to inform optimal care and wellbeing of families.

## **Strategic Objective 1:**

### **Accelerate the national response for childhood and adolescent cancer care in Sri Lanka through an integrated national programme with leadership, advocacy and governance**

The Global Initiative on Childhood Cancer (GICC) was declared in 2018 to reach at least 60% survival rate for children with cancer by 2030 while reducing sufferings of patients and their families who live with childhood cancer (7). Sri Lanka also aiming to attain these targets by 2030. Thus, developing a National Strategic Plan for childhood and adolescent cancer care is essential in conducting interventions to achieve the above mentioned targets. High level political commitment is very much needed and good governance will provide a strong foundation to make this effort a success. Even though, primary contributor for this task is health sector, to achieve targets in a fruitful way, the engagement of several stakeholders is essential.

Advocacy targeting high level decision makers is required to have a sustainability of the programme. The leadership for such development is mandatory to reach the financial pillar and facilitate the requirements needed to nourish the interventions which are needed to attain objectives.

There should be a strong foundation at the central level to provide leadership and coordinate among relevant authorities namely, health & non-health government institutions, private sector institutions, non-governmental institutions, community-based organizations, children living with cancer and caregivers etc. to work in partnership. All the performances will be monitored and evaluated using a Results Framework which will be developed according to national and international standards, using SMART indicators. The first strategy of NSP on childhood and adolescent cancer care control focuses on leadership, advocacy and governance which stands as the backbone of the overall process.

### **Strategic Objective 1:**

## **Accelerate the national response for childhood and adolescent cancer in Sri Lanka through an integrated national programme with leadership, advocacy and governance**

### **Strategic direction 1.1 Recognize childhood and adolescent cancer care as a prioritized action area of delivery of cancer care in Sri Lanka**

1.1.1	Assess the service requirements and progress of interventions of childhood and adolescent cancer care as a separate thematic area at the meetings of the National Advisory Committee (NAC) on Prevention & Control of Cancers and communicate to the relevant authorities for further action.
1.1.2	Establish a Technical Advisory Committee for Childhood and Adolescent Cancer Care in Sri Lanka with Terms of Reference (TOR)

### **Strategic direction 1.2 Identify sustainable financing mechanisms to scale up optimal childhood and adolescent cancer care ensuring universal health coverage**

1.2.1	Allocate and ensure utilization of funds according to the priorities that have been previously identified.
1.2.2	Create a mechanism to monitor allocated amounts, annual utilization and yearly incremental needs of finances for childhood and adolescent cancer care
1.2.3	Implement measures to minimize the rising cost of Out of Pocket Expenditure (OPE) for childhood and adolescent cancer care
1.2.4	Identify gaps and further strengthen insurance schemes that are available for childhood and adolescent cancer care (Eg. 'Suraksha' insurance introduced by the Ministry of Education)
1.2.5	Increase visibility of other government/civil society led welfare support services available for children with cancer

**Strategic direction 1.3: Ensure adequate health workforce for childhood and adolescent cancer care extending from specialized centres to primary and secondary care.**

1.3.1	Develop a Master Plan for human resources for childhood and adolescent cancer care development <i>(1.2.6 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>
1.3.2	Advocate appointment of Paediatric Oncologists to National Hospital Kandy (or Sirimavo Bandaranayake Specialized Children's Hospital, Peradeniya), TH Karapitiya, TH Anuradhapura, TH Batticaloa & TH Jaffna in a phased manner. <i>(4.5.1 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>
1.3.3	Establish relevant cadre positions (Medical officers, Nursing officers and other paramedical staff) to the designated Paediatric Oncology units
1.3.4	Develop and implement capacity building plans (basic, postgraduate, in service) to ensure trained health care staff for delivery of all aspects of childhood and adolescent cancer care. <i>(1.2.8 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>

**Strategic direction 1.4: Ensure national master plans are available for infrastructure development and supply of logistics for childhood and adolescent cancer care**

1.4.1	Develop a master plan for infrastructure development for childhood and adolescent cancer care <i>(1.2.7 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>
1.4.2	Establish a procurement supply and management plan for diagnostics, pharmaceuticals and non-pharmaceutical devices for childhood and adolescent cancer care <i>(1.2.9 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>

**Strategic direction 1.5: Create a culture of networking and facilitate team approach for delivery of childhood and adolescent cancer care extending from specialized centres to primary and secondary care.**

1.5.1	Establish a network connecting the national, provincial cancer treatment centres and other relevant hospitals & professionals for updates and experience sharing for diagnosis, treatment and follow up childhood and adolescent cancers.
1.5.2	Facilitate Multi-Disciplinary Team (MDT) approach for all aspects (diagnosis, treatment, rehabilitation, survivorship care, palliative care) of childhood and adolescent cancer care

## **Strategic Objective 2:**

### **Ensure timely and accurate diagnosis of childhood and adolescent cancers in Sri Lanka**

Timely and accurate diagnosis at an early stage of childhood and adolescent cancer improves the survival rates and quality of life. Even though screening plays an important role in adult cancers, it is not a practical strategy for timely diagnosis in childhood and adolescent cancer, since childhood cancers usually cannot be prevented or detected by screening (9). Therefore, the main focus would be the timely and accurate diagnosis and notable improvements can be seen in the children living with cancers. An accurate diagnosis is crucial to initiate the treatment for children with cancers since, different cancers have their own treatment modalities such as surgery, chemotherapy and radiotherapy (10).

Early and accurate diagnostic facilities have been implemented in almost all developed countries and some developing countries successfully with the partnership of governmental and non-governmental organizations. This National Strategic Plan on Childhood and Adolescent Cancer Care introduce interventions to develop infrastructure space and quality services utilizing standard guidelines to ensure availability, accessibility and affordability of diagnostic facilities and treatment facilities adhering to the universal health coverage concept.

## **Strategic Objective 2: Ensure timely and accurate diagnosis of childhood and adolescent cancers in Sri Lanka**

### **Strategic Direction 2.1 Facilitate the process of diagnosis of childhood and adolescent cancers through a multidisciplinary approach**

2.1.1	Conduct regular refresher programmes for general Paediatricians and general practitioners on the diagnosis of childhood and adolescent cancers
2.1.2	Conduct regular refresher programmes and introduce interactive distant learning modules for primary care medical officers /general practitioners on Childhood & adolescent cancers
2.1.3	Empower parents and teachers on early suspicious symptoms of cancers through appropriate messages without creating fear psychosis
2.1.4	Create an updated proforma for reporting childhood and adolescent cancers to ensure uniformity of reporting
2.1.5	Establish networked laboratory reporting system for sharing patient and tumour information
2.1.6	Facilitate multidisciplinary approach including Tumour boards in the diagnosis of childhood and adolescent cancer
2.1.7	Ensure follow up mechanism for children with cancer predisposing syndromes at Paediatric units

### **Strategic direction 2.2: Strengthen histopathology laboratory services for diagnosis of childhood and adolescent cancers**

2.2.1	Develop and implement guidelines for procedure manuals in histopathology laboratory services for diagnosis of childhood and adolescent cancers.
2.2.2	Establish immunohistochemistry laboratory facilities at the specialized Paediatric hospitals (LRH-Colombo and SBCH-Peradeniya) with human resources, equipment and continuous supply of consumables including reagents for diagnosis of childhood and adolescent cancers.
2.2.3	Establish a mechanism to review and report the Paediatric pathology samples by Pathologists at centres where Paediatric tumours are commonly seen.



2.2.4	Provide a special training for Pathologists prior to take up posts in Paediatric hospitals.
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**Strategic direction 2.3: Strengthen Haematology laboratory services for diagnosis of childhood and adolescent cancers**

2.3.1	Ensure availability of flow cytometry facilities at the hospitals with Pediatric Cancer Units and Lady Ridgeway Hospital for Children
2.3.2	Ensure regular supply of reagents for Minimal Residual Disease (MRD) analysis for Leukaemia.
2.3.3	Develop guidelines on Haematological diagnosis and follow up for childhood and adolescent cancers and ensure implementation
2.3.4	Provide regular training to the Haematology staff on diagnosis of childhood and adolescent cancer.
2.3.5	Allocate at least one machine for the country as a national reference centre for RT - PCR at the National Cancer Institute of Sri Lanka (NCISL)

**Strategic direction 2.4: Strengthen chemical pathology laboratory services for diagnosis of childhood and adolescent cancers**

2.4.1	Ensure availability of reagents to chemical pathology laboratories for diagnosis and follow up of childhood and adolescent cancers
2.4.2	Develop guidelines on chemical pathology diagnosis and follow up for childhood and adolescent cancers.
2.4.3	Provide special training to the chemical pathology staff on diagnosis of childhood and adolescent cancer

**Strategic direction 2.5: Strengthen molecular & genetic testing facilities for diagnosis of childhood and adolescent cancers**

2.5.1	Establish molecular, cytogenetics and genetic testing facilities at National Cancer Institute of Sri Lanka  <i>(4.2.4.3 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>
2.5.2	Ensure availability of relevant technical staff including laboratory technicians, bioinformatician, clinical geneticist, genetic diagnostic technicians, scientists and molecular biologists to National Cancer Institute of Sri Lanka.
2.5.3	Develop national genetic diagnostic guidelines and protocols for Childhood and adolescent cancers

**Strategic direction 2.6: Strengthen radiological services for diagnosis of childhood and adolescent cancers**

2.6.1	Ensure facilities (Anaesthetist, anaesthetic machine) to conduct PET/ CT under general anaesthesia at National Cancer Institute of Sri Lanka
2.6.2	Establish PACS system for sharing patient information within and between hospitals. (Connecting LRH and NCISL).
2.6.3	Ensure 3 D MRI facility at National Cancer Institute OF Sri Lanka minimizing transferring patient to other hospitals for MRI  <i>(4.2.2.2 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>
2.6.4	Provision of PET CT/ PET MRI to LRH
2.6.5	Appoint interventional radiologists /Paediatric Radiologists to main Paediatric hospitals/teaching hospitals/ Provincial General hospitals ensuring access to biopsies of Paediatric solid tumours
2.6.6	Ensure good X rays/ good USS for secondary and tertiary care hospital facilitating early diagnosis

### **Strategic Objective 3:**

#### **Improve comprehensive cost-effective treatment options for childhood and adolescent cancers including chemotherapy, radiotherapy, surgery and novel therapeutic modalities.**

Childhood cancer is different from adult cancer and its treatment protocols also differ from each other. It is accepted that there are successful treatment options for many childhood cancers including surgery, chemotherapy, radiation therapy, immunotherapy and stem cell transplant. For a better treatment outcome, childhood cancer should be handled by a multidisciplinary team with relevant expertise, where shared decision making is practiced.

This strategy addresses the areas of treatment which need further enhancing the facilities to maintain continuum of care in childhood cancer. As an apex, Centre of Excellence (CoE) will be established to use it as the core of providing all the updated diagnostic and treatment facilities. As the first step, National Centre of Excellence in Cancer Care for children and adolescents is established in National Cancer Institute of Sri Lanka. Similarly, to provide comprehensive paediatric surgical care for childhood cancers, surgical care services at Lady Ridgeway Hospital for children: The Premier Children Hospital in the country, need to be strengthened as an initial step.

It is promoted to provide patient centred care by a multidisciplinary team adhering to guidelines and protocols which will be generated by experts using evidence-based knowledge for management of childhood and adolescent cancer care. In addition to that, to provide the service in an equitable manner throughout the island, other treatment centres at tertiary and secondary hospitals will link with the national centre. In the management of childhood and adolescent cancer, it is not solely focused on treatment modalities, but also rehabilitation, survivorship care, psychological counselling, palliative care for the patients and their families. Meanwhile, it is important to ensure optimal pain management which will be much more concerned and adequate actions will be proposed in delivering pain free care.

Further, this strategic plan on childhood and adolescent cancer aims to provide quality Oncology services including availability of essential drugs, continuous supply of medicines, continuous training needed on delivering cost effective treatment options for childhood and adolescent cancers.

### Strategic Objective 3:

**Improve comprehensive cost-effective treatment options for childhood and adolescent cancers including chemotherapy, radiotherapy, surgery and novel therapeutic modalities.**

**Strategic direction 3.1: Develop National Cancer Institute of Sri Lanka as the centre of excellence for childhood and adolescent cancer care in Sri Lanka**

3.1.1	Strengthen existing Paediatric Cancer Treatment Unit at National Cancer Institute of Sri Lanka incorporating essential services for provision of comprehensive care
3.1.2	Expedite the construction of the proposed Childhood and adolescent cancer care unit (including modern Paediatric cancer care unit with separate sub units for adolescent cancer patients, ICU and HDU.....etc.) at NCISL ( <i>Razavi Project II</i> ).
3.1.3	Facilitate liaising of National Cancer Institute Sri Lanka with Childhood Cancer Care Network (CCN) of WHO SEAR Office to promote a connected and integrated cancer care improvement
3.1.4	Facilitate liaising of National Cancer Institute Sri Lanka with international collaborators such as St. Jude Global Alliance (SJGA) of St. Jude Hospital for Paediatric cancers in USA to promote a connected and integrated cancer care improvement
3.1.5	Establish telemedicine facilities for cancer care including follow up care with other cancer treatment centres and main hospitals (4.5.4 of NSP on Prevention & Control of Cancers 2020 - 2024)

**Strategic direction 3.2: Strengthen childhood and adolescent cancer care at the identified cancer treatment centres in the country inequitable manner**

3.2.1	Scale up dedicated Paediatric Oncology services at National Hospital Kandy (or Sirimavo Bandaranayake Specialized Children's Hospital, Peradeniya), TH Karapitiya, TH Anuradhapura and BH Telippalai/TH Jaffna in a phased manner to ensure equitable access to Paediatric cancer care (4.5.1 of NSP on Prevention & Control of Cancers 2020 - 2024)
3.2.2	Strengthen up providing facilities in already established Oncology units for care of these patients

### Strategic direction 3.3: Strengthen comprehensive care for childhood and adolescent cancer patients at the identified cancer treatment centres

3.3.1	Develop & introduce guidelines/protocols /SOPs for management of childhood and adolescent cancer care <i>(4.5.2 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>
3.3.2	Encourage and facilitate multi-disciplinary team based (MDT) decision making at least for the complicated cases of childhood and adolescent cancers
3.3.3	Introduce Paediatric cancer early warning system (PEWS) and train the health care team to detect early sepsis and organ dysfunction to improve overall outcomes of children with cancer
3.3.4	Expand day care treatment facilities for Paediatric and adolescent cancer patients <i>(4.5.2 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>
3.3.5	Improve access to supportive care facilities including nutrition, growth and development as well as other general Paediatric care needs in children and adolescents with cancers
3.3.6	Improve measures to minimize cross infections among childhood & adolescent cancer patients in hospital setting
3.3.7	Develop and implement an in-service training module including hands on training for newly appointed medical officers for the Paediatric Oncology units
3.3.8	Develop and implement an in-service training programme for nursing staff at the Paediatric oncology Units
3.3.9	Establish Clinical nutrition unit and availability of nutrition support at any given time.

**Strategic direction 3.4: Improve care at the intensive care units and emergency treatment units for critically ill childhood and adolescent cancer patients**

3.4.1	Assess the needs of intensive care facilities affiliated to Paediatric Oncology units and improve the facilities according to the need
3.4.2	Develop and implement guidelines for management of childhood cancer patients admitted to emergency treatment units for early identification and relevant interventions for Oncological emergencies (eg. Febrile neutropenia, Tumour lysis syndrome ... etc) .

**Strategic direction 3.5: Ensure availability of quality assured medicines in appropriate strengths and dosage forms for childhood and adolescent cancer care**

3.5.1	Develop a National Essential Medicine List (NEML) for Childhood cancer to ensure availability of essential Paediatric Oncology medicines without stock-out situations in appropriate strengths and dosage forms <i>(4.5.3 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>
3.5.2	Strengthen the existing mechanism to monitor the needs, the volumes received and volumes utilized, periods of stock-out situations etc.. to ensure continuous delivery of medicines in appropriate strengths and dosage forms in collaboration with MSD.
3.5.3	Develop and implement a sustainable quality assurance mechanism to ensure availability of good quality medicines for Paediatric Oncology care
3.5.4	Enhance good distribution practices and storage of childhood cancer drugs at the childhood cancer treatment centres
3.5.5	Ensure special allocation of funds at the Ministry of Health and at the cancer treatment centres to purchase drugs locally that are not available under special circumstances with the concurrence of National Medicines Regulatory Authority (NMRA).
3.5.6	Develop a network for Paediatric Oncology medicine users to monitor safety of the medicines and offer pharmacovigilance services in collaboration with NMRA.
3.5.7	Establish a mechanism to purchase the non -formulary drugs whenever needed for rare childhood cancers

3.5.8	Ensure provision of therapeutic nutrition for needy childhood cancer patients
3.5.9	Advocate for appointment of Clinical Pharmacologist to National Cancer Institute of Sri Lanka & establishing clinical pharmacology unit
3.5.10	Further strengthen the mechanism to obtain civil society support for provision of drugs for childhood cancer patients

### **Strategic direction 3.6: Strengthen surgical care for childhood and adolescent cancer care**

3.6.1	Link Paediatric surgical care services (Paediatric surgery, Surgical subspecialties – Orthopedics, Neurosurgery, Ophthalmology, ENT surgery, Oncosurgery, Thoracic surgery) with the Paediatric Oncology services, pathology services and Radiology services
3.6.2	Conduct situation analysis of surgical care needs for childhood and adolescent cancers and prioritize interventions
3.6.3	Strengthen Paediatric surgical units (Paediatric surgery, Surgical subspecialties – Orthopaedics, Neurosurgery, Ophthalmology, ENT surgery ..... ) at Lady Ridgeway Hospital for children for advanced surgical management of Paediatric cancers
3.6.4	Ensure availability of surgical products needed for treating of childhood cancers (venous access devices, surgical instruments including bone marrow needles, Paediatric orthopaedic bone tumour instruments, implants) – mega prostheses
3.6.5	Facilitate clinical audits at the Paediatric surgical units on Childhood and Adolescent Cancer Care
3.6.6	Networking with an International Paediatric Surgical Care Network for further enhancement of Childhood and Adolescent Cancer Care

### **Strategic direction 3.7: Strengthen radiotherapy facilities for childhood and adolescent cancer care**

3.7.1	Ensure access to quality radiotherapy services for all children who need this modality by having dedicated radiotherapy slots
3.7.2	Establish teams consisting of physicists, therapy radiographers, nurses and support staff trained in handling children needing Radiotherapy.
3.7.3	Ensure adequate anaesthetic support for children needing radiotherapy.
3.7.4	Ensure availability of Paediatric size immobilization devices, applicators, moulds for radiotherapy for children and adolescents with cancer
3.7.5	Networking with Paediatric radiotherapy professional group for enhancement of radiotherapy care

### **Strategic direction 3.8: Strengthen microbiological services for childhood and adolescent cancer care**

3.8.1	Strengthening microbiology services for early diagnosis of sepsis among children and adolescents with cancers
3.8.2	Minimize disruption to childhood cancer care due to COVID 19 pandemic
3.8.3	Development and implementation of anti-microbial stewardship programme for minimizing antimicrobial resistance

### **Strategic direction 3.9: Commence of advanced treatment options for childhood and adolescent cancer care**

3.9.1	Establish stem-cell transplantation (both autologous & allogenic) for childhood cancer care at the National Cancer Institute of Sri Lanka
3.9.2	Create special training programme for medical officers and nursing officers to initiate stem cell transplantation for childhood cancers



**Strategic direction 3.10: Introduce total pain free procedures for the treatment of childhood and adolescent cancer care**

3.10.1	Establish pain free procedures at childhood cancer care
3.10.2	Ensure minimal side effects and discomfort due to Paediatric cannulation
3.10.3	Establish a procedure room per ward for each Paediatric Oncology unit
3.10.4	Appoint a designated “pain team” including a Consultant Anesthetist at each childhood cancer treatment centre

**Strategic direction 3.11: Address to specific psycho- social and spiritual needs of children and adolescents with cancer**

3.11.1	Develop a mechanism to address to psychosocial needs of childhood and adolescent cancer patients and their family members
3.11.2	Develop mechanism to ensure continuity of school education while the child is receiving inward care
3.11.3	Establish a family room for counselling (eg. Breaking serious news) for each unit at Paediatric hospitals and other diagnostic centres.
3.11.4	Establish parent support groups to continue the journey with the affected child
3.11.5	Establish peer support groups/Bravery groups
3.11.6	Improve the community and home care linking primary health care teams
3.11.7	Develop partnerships with other government and non-government organizations to ensure extended support for children and adolescents with cancer

#### **Strategic Objective 4:**

**Ensure access to rehabilitation & long-term survivorship care for the patients with childhood and adolescent cancers facilitating family support & community engagement.**

Over the past years, with the development of diagnostic and treatment facilities, the number of survivors of childhood cancer has increased considerably (11). Global estimates report that around 25% of survivors of childhood cancer have faced long-term complications like cardiopulmonary dysfunction, subsequent malignant neoplasms, endocrinopathies, and neurosensory disorders, psychological disorders. Unlike adults, children and adolescents bear acute consequences of treatment relatively well. Nevertheless, different treatment modalities such as radiation, chemotherapy and surgery at early ages can cause complications later in life (12).

In Sri Lanka, annually around 700 childhood cancer cases detected and they require multi-disciplinary survivorship care during their transition from childhood into adulthood (13). This will challenge the health care system to ensure appropriate long-term follow up care to improve quality of life among survivors. In this backdrop, recognizing the need for a plan and guidelines for lifelong surveillance among children with cancers is essential.

Rehabilitation is interrelated with the chronic diseases. The suitable rehabilitation strategy differs with the type of the child's cancer, treatment and prognosis. Rehabilitation is a prime aspect in dynamic problem solving among children with cancers as they grow even into adulthood. Dietz classification in cancer rehabilitation focuses the planning interventions through preventative, restorative, supportive and palliative approaches (14).

The NSP on childhood and adolescent cancer care has identified the rehabilitation and long-term survivorship care as essential components in continuum of care. This NSP will address the infrastructure facilities, human resource development, capacity building and integration of Oncology with other relevant streams such as general Paediatrics, social service department and education etc.

## **Strategic Objective 4:**

**Ensure access to rehabilitation & long-term survivorship care for the patients with childhood and adolescent cancers facilitating family support & community engagement.**

### **Strategic direction 4.1: Access to counselling services for the patients with childhood and adolescent cancers and their families**

4.1.1	Strengthen specially trained counselling team at National Cancer Institute of Sri Lanka and Lady Ridgeway Hospital for Children (LRH) for the patients with childhood & adolescent cancers
4.1.2	Design formal training programmes on the basics of communication and counselling for the medical, nursing staff and other categories of staff working at the Paediatric cancer units
4.1.3	Establish specially trained counselling teams at the relevant hospitals where the childhood & adolescent cancer patients are being treated. (These counselling teams need to provide services to Paediatric surgical units, Neuro surgical Units, Orthopaedic units, ENT units, Ophthalmology units in addition to the oncology units when needs arise)

### **Strategic direction 4.2: Ensure access to rehabilitation services for childhood and adolescent cancers**

4.2.1	Strengthen provision of services for the rehabilitation needs of patients with childhood and adolescent cancers
4.2.2	Commence dedicated rehabilitation clinic service for the survivors of childhood and adolescent cancers
4.2.3	Refresher training for physiotherapists, occupational therapists and speech therapists in relation to provision of services for the survivors of childhood and adolescent cancers
4.2.4	Networking with other stakeholders for provision of rehabilitation services.

### **Strategic direction 4.3: Ensure long term survivorship care for childhood and adolescent cancers**

4.3.1	Strengthen Paediatric cancer survivorship care programme (physical, psychological, social, spiritual) at NCISL for the patients with childhood and adolescent cancers.
4.3.2	Develop long term survivorship care plan for each survivor in collaboration with the child and family.
4.3.3	Communicate survivorship care plan to family, primary care physician, school of the child and social service officer, etc..
4.3.4	Strengthen and follow up educational interventions for childhood and adolescent cancer survivors
4.3.5	Establish a survivorship clinic for long-term follow up patients at Paediatric cancer units.

### **Strategic direction 4.4: Strengthen family and community empowerment for childhood and adolescent cancers**

4.4.1	Conduct informal care giver training programmes for family members of children and adolescents with cancers.
4.4.2	Empower primary care medical officers & nursing staff (including PHNOs) on follow up care for patients with childhood and adolescent cancers in the community setting
4.4.3	Consider childhood cancer to be categorized as a special disease entity for funding of Social Services Department during active treatment phase.
4.4.4	Establish a network of friends & well-wishers of Paediatric cancer unit to formalize philanthropic contributions for childhood cancer care
4.4.5	Ensure welfare of families affected by childhood cancers
4.4.6	Establish mental health services to address psychological issues including sexual problems in adolescence cancers.

## **Strategic Objective 5:**

### **Ensure access to palliative care services for the needy patients with childhood and adolescent cancers and their families**

As WHO elaborates, that palliative care “improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” It should be more patient centred and should be available at all the levels of care (15). The Worldwide Palliative Care Alliance identifies the significance of amalgamating palliative care as a human right for children, even in a health system where the resources are lacking (16). The support for patients and their families should be established not only while on inpatients care but also on home care. Hence the palliative care concepts should be incorporated early into the system to bridge the continuum of care throughout their lives.

The confidence and the ability of the family to care for their child at home should be enhanced and the required knowledge and training can be given to the caregivers. Especially terminally ill children should be treated with optimal care even at the hospital as well as at home. Several studies report that palliative care services (hospital based and community based) have the ability to improve the quality of life, reduce hospital stay, less invasive treatment and symptom control (17,18).

When considering the systematic plan for palliative care, they should be treated in a novel way, understanding that children are not little adults. In this strategic plan, it is recognized to develop appropriate guidelines and protocols to Paediatric palliative care services, infrastructure development like rainbow rooms, capacity building and improving home-based palliative care services throughout the island in an equitable manner. Additionally, this NSP on childhood and adolescent cancer encourages the collaboration of government and non- government institutions to provide home based palliative care and empower their families and caregivers for supplying basic palliative care.

## Strategic Objective 5:

Ensure access to palliative care services for the needy patients with childhood and adolescent cancers and their families

Strategic direction 5.1: Provide palliative care services for the children and adolescents with cancers

5.1.1	Develop SOPs related to Paediatric palliative care services
5.1.2	Form a Paediatric palliative care team at National Cancer Institute of Sri Lanka through a well-designed training programme
5.1.3	Provide special training to palliative care teams in other Oncology units of the country caring for children and adolescents with cancer
5.1.4	Establish a dedicated facility (Eg. "rainbow rooms") for terminal care for care for the patients with childhood and adolescent cancers at the Paediatric Oncology units
5.1.5	Develop and establish a shared care plan for palliative care services for the patients with childhood and adolescent cancers according to the need
5.1.6	Form trained primary palliative care teams (including primary care doctors, public health nursing officers and other healthcare workers) in the community level for community-based palliative care including bereavement care according to the need liaising with the Paediatric Oncology unit
5.1.7	Empower caregivers to carry out home-based palliative care for patients with childhood and adolescent cancers according to the need.
5.1.8	Develop a mechanism for networking with the government and non-government institutions providing palliative care for children and adolescents
5.1.9	Collaboration with NGOs for financial support and volunteers to optimize existing facilities. Eg: Hospices for Paediatric patients.
5.1.10	Establishment of young Oncology care group to share experience and support with treatment related side effects, complications and compliance.

## Strategic direction 5.2: Empowering health care teams and other stakeholders through education

5.2.1	Incorporate Paediatric palliative care module to MD and Diploma programme in Palliative Medicine conducted by the Post Graduate Institute of Medicine
5.2.2	Incorporate of module on Paediatric palliative care in Post basic nursing programme on palliative nursing
5.2.3	Incorporate Paediatric palliative care session to basic, in-service training programmes of health care staff.
5.2.4	Incorporate Paediatric & Adolescence palliative care to the curriculum of and BSc nursing degree
5.2.5	Public Health Nursing Officers are empowered with inputs on Paediatric palliative care inputs to act upon if need arise
5.2.6	Establish Bereavement care and funeral support mechanism

## **Strategic Objective 6:**

### **Strengthen management information systems including cancer registries and comprehensive medical records to monitor the progress and evaluate the outcomes of childhood and adolescent cancers.**

Cancers are multifactorial diseases which have complex pathogenesis. With the increasing burden of childhood cancers, variety of data is generated during its diagnosis and therapeutic process. It is salient to design an information system specially for childhood cancers to improve the accessibility, management and organization of childhood cancer related data. The purpose of the childhood cancer information system is to prepare systematic, accurate, timely and complete data on childhood cancer. As reported in the literature, there are numbers of benefits which can be gained from an information system in cancer such as improving quality of clinical care, increasing accessibility of information at the point of need, reducing time of clinical documentation, facilitating outcome reporting, maintaining confidentiality, improving resource allocation and providing rich data for clinical trials (19).

The National Cancer Control Programme of the Ministry of Health with the collaboration of the National Cancer Institute of Sri Lanka will be committed to establish a hospital-based childhood and adolescent cancer registry to monitor the progress and evaluate the outcomes of childhood and adolescent cancers and Hospital-based childhood and adolescent cancer registries will be expanded to other Paediatric and adolescent Oncology units with time. Additionally, this NSP proposes to commence population-based childhood & adolescent cancer registry in the Colombo district utilizing existing cancer registry infrastructure and analyzing data using the International Classification of Childhood Cancer.



## Strategic Objective 6:

**Strengthen management information systems including cancer registries and comprehensive medical records to monitor the progress and evaluate the outcomes of childhood and adolescent cancers**

**Strategic direction 6.1: Strengthen cancer registries to monitor the progress and evaluate the outcomes of childhood and adolescent cancers.**

6.1.1	Establish hospital-based childhood and adolescent cancer registry on par with IARC standards (including treatment details, follow up details and survival rates) at the National Cancer Institute of Sri Lanka
6.1.2	Establish a mechanism to share relevant data of the hospital-based childhood and adolescent cancer registry at the NCISL with the National Cancer Registry Programme of Sri Lanka
6.1.3	Commence Population-Based Cancer Registry of Childhood Cancers (PBCR of Childhood Cancers) in Colombo district utilizing existing populationbased cancer registry infrastructure and analyzing data using International Classification of Childhood Cancer, Third edition (ICCC-3) in par with global initiative of childhood cancer registries (Child GICR)
6.1.4	Improve the section of childhood & adolescent cancer incidence & mortality data with additional outputs in the National Cancer Registry Programme towards developing national population based childhood cancer registry
6.1.5	Commence hospital-based childhood & adolescent cancer registries in other Paediatric and adolescent Oncology units in the country
6.1.6	Provide necessary infrastructure support to facilitate efficient data collection within NCISL and outside

**Strategic direction 6.2: Strengthen management information systems to monitor the progress and evaluate the outcomes of childhood and adolescent cancers.**

6.2.1	Establish a network connecting the central and provincial Paediatric cancer centres with the details and updates of the current condition and management of the individual patients.
6.2.2	Conduct the reviews of Childhood and adolescent cancer morbidity and mortality with the participation of Hospital Administrators, Consultant Paediatric Oncologists, Paediatricians, Paediatric surgeons, Radiologists, Histopathologists, Haematologists, Public Health & Primary Care Physicians, ..... etc

## **Strategic Objective 7:**

### **Promote research related to childhood and adolescent cancers and utilization of its findings to inform optimal care**

Cancer research is essential to improve the prevention, diagnosis, treatment, survivorship care for better quality lives among people living with cancers and their families. Often these factors are unique to regions and even countries. Therefore, homegrown research plays an important role in developing when trying to improve childhood cancer outcomes.

This strategic plan specifically focuses on childhood cancer care which includes broad research areas such as epidemiology, laboratory research, clinical, health systems and policies. Scientific evidence on incidence, mortality, survival rates, survivorship care, caregiver burden etc will be helpful not only in understanding the epidemiology and existing health system but also human resource development and infrastructure development. It is very important to focus on locally conducted research, since the evidence can be utilized to influence policy, administrative, clinical decision making.

### **Strategic Objective 7:**

### **Promote research related to childhood and adolescent cancers and utilization of its findings to inform optimal care**

#### **Strategic direction 7.1: Promote of research related to childhood and adolescent cancers**

7.1.1	Identify research priorities in relation to childhood and adolescent cancers in Sri Lankan setting (Epidemiological /Basic sciences / Clinical/ Health System)
7.1.2	Increase funding opportunities for research on childhood and adolescent cancers
7.1.3	Promote undergraduate and post graduate research related to childhood and adolescent cancers
7.1.4	Establish a research facility with logistical support to conduct research related to childhood and adolescent cancers at the Paediatric Oncology unit, NCISL.
7.1.5	Facilitate joining in international childhood and adolescent cancer clinical trials and research activities that will directly benefits Sri Lankan patients
7.1.6	Establish a research hub focusing on childhood and adolescent cancer, enetic etiological basis and palliative care

#### **Strategic direction 7.2: Facilitate utilization of research evidence for clinical practice and service improvements**

7.2.1	Facilitate conducting journal clubs, research seminars related to childhood and adolescent cancers
7.2.2	Utilize locally conducted research to inform clinical, policy, administrative decision making
7.2.3	Publish and present the research findings in local & international forum



**Activity plan of Childhood and Adolescent  
Cancer Care in Sri Lanka  
2021-2025**

**Strategic Objective 1: Accelerate the national response for childhood and adolescent cancer care in Sri Lanka through an integrated national programme with leadership, advocacy and governance**

<b>Strategic Direction 1.1 - Recognize childhood and adolescent cancer care as a prioritized action area of delivery of cancer care in Sri Lanka</b>							
<b>Major Activities</b>	<b>Sub activities</b>	<b>Responsibility</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024</b>	<b>2025</b>
1.1.1 Assess the service requirements and progress of interventions of childhood and adolescent cancer care as a separate thematic area at the meetings of the National Advisory Committee (NAC) on Prevention & Control of Cancers and communicate to the relevant authorities for further action	Ensure the service requirements on childhood and adolescent cancer care is discussed in every meeting of the National Advisory Committee (NAC) on Prevention & Control of Cancers.	DDG (NCD), Director- NCCP	X	X	X	X	X
1.1.2 Establish a Technical Advisory Committee for Childhood and Adolescent Cancer Care in Sri Lanka with Terms of Reference (TOR) (Identify a focal point in the Ministry of Health to coordinate childhood cancer activities)	Identify members for Technical Advisory Committee for Childhood and Adolescent cancer care with TOR	DGHS, DDG- NCD, Director - NCCP		X	X	X	X
	Allocate responsibilities as per TORs for each member			X	X	X	X
<b>Strategic Direction 1.2: Identify sustainable financing mechanisms to scale up optimal childhood and adolescent cancer care ensuring universal health coverage</b>							
1.2.1 Allocate and ensure utilization of funds according to the priorities that have been previously identified	Inform relevant DDGs and directorates to include adequate funds for the upcoming year and allocate funds in each year activity plan	DGHS, DDG -Planning, DDG - NCD		x	x	x	x

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
1.2.2 Create a mechanism to monitor allocated amounts, annual utilization and yearly incremental needs of finances for childhood and adolescent cancer care	Appoint a sub-committee under the Technical Advisory Committee for Childhood and Adolescent Cancer Care in Sri Lanka	TAC on Childhood and Adolescent Cancer, DDG - NCD, Director - NCCP		x	x	x	x
	Present the progress in every TAC committee			x	x	x	x
	Identify incremental needs of finances for childhood and adolescent cancer care			x	x	x	x
1.2.3 Implement measures to minimize rising cost of Out of Pocket Expenditure (OPE) for childhood and adolescent cancer care	Identify the current burden and reasons of increasing OPE	TAC on Childhood and Adolescent Cancer, DDG - NCD, Director - NCCP		x	x	x	x
	Develop interventions to minimize rising cost of Out of Pocket Expenditure (OPE)				x	x	x
	Identify and coordinate with NGO/civil welfare societies for identified interventions				x	x	x
1.2.4 Identify gaps and further strengthen insurance schemes for childhood and adolescent cancer care (Eg. 'Suraksha' insurance introduced by the Ministry of Education)	Communicate with Ministry of Education and facilitate necessary steps to identify gaps and further strengthen insurance scheme	TAC on Childhood and Adolescent Cancer, Ministry of Education		x	x	x	x
1.2.5 Increase visibility of other government/civil society led welfare support services available for children with cancer	List the services provided by other government/civil society led welfare support services available for children with cancer	TAC on Childhood & Adolescent Cancer , Director - National Cancer Institute, Director -NCCP, Director - Social Service Department		x	x	x	x
	Annual review of services provided by other government/civil society led welfare support services available for children with cancer						



Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
<b>Strategic direction 1.3 : Ensure adequate health workforce for childhood and adolescent cancer care extending from specialized centres to secondary and primary care.</b>							
1.3.1 Develop a Master Plan for human resources for childhood and adolescent cancer care development (1.2.6 of NSP on Prevention & Control of Cancers 2020 - 2024)	Establish a sub-committee under TAC on Childhood cancer to identify human resource needs for Childhood and adolescent cancer for next 10 years & develop a plan	TAC on Childhood & Adolescent Cancer		X			
	Incorporate identified human resource plan to the Health Master Plan on Human Resources	DGHS, DDG (Planning)			X		
1.3.2 Advocate appointment of Paediatric Oncologists to National Hospital Kandy (or Sirimavo Bandaranayake Specialized Children's Hospital, Peradeniya), TH Karapitiya, TH Anuradhapura, TH Batticaloa & TH Jaffna in a phased manner.(4.5.1 of NSP on Prevention & Control of Cancers 2020 - 2024)	Considering the availability, appointment of Paediatric Oncologist according to the priority order recommended by the TAC on Childhood and Adolescent Cancer	DGHS, DDG (MS 1)			X	X	X
1.3.3. Establish relevant cadre positions (Medical officers, Nursing officers and other para-medical staff) to the designated Paediatric Oncology units	Identify the relevant cadre positions for Childhood and Adolescent cancer care	DDG (Planning), DDG (MS - 2), DDG (Administration)		X	X		
	Inform the identified cadres for approval by the salaries and cadre Commission				X	X	
	Appoint relevant officers according to the approved cadre					X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
1.3.4 Develop and implement capacity building plan (basic, postgraduate, in service) to ensure trained health care staff for delivery of all aspects of childhood and adolescent cancer care <i>(1.2.8 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>	Identify the relevant capacity building needs of childhood & adolescent cancer care and incorporate to the basic & in-service training programmes according to the staff categories	TAC on Childhood & Adolescent Cancer, DDG (ET & R)		X	X	X	X
	Identify the relevant capacity building needs of childhood & adolescent cancer care and incorporate to the Undergraduate & Post -Graduate programmes according to the staff categories	Faculties of Medicine, Medical Sciences, Nursing an allied health Sciences, Post Graduate Institute of Medicine		X	X	X	X
<b>Strategic direction 1.4: Ensure national master plans are available for infrastructure development and supply of logistics for childhood and adolescent cancer care</b>							
1.4.1 Develop a master plan for infrastructure development for childhood and adolescent cancer care <i>(1.2.7 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>	Develop a Master plan for infrastructure development for Childhood and adolescent cancers	TAC on Childhood & Adolescent Cancer, DDG (Planning)		X	X		
1.4.2 Establish a procurement supply and management system for diagnostics, pharmaceuticals and non-pharmaceutical devices for childhood and adolescent cancer care <i>(1.2.7 of NSP on Prevention &amp; Control of Cancers 2020 - 2024)</i>	Develop the procurement supply and management system for childhood and adolescent cancer care	DDG (MSD), DDG Logistics, Director - Information, Director- National Cancer Institute		X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
<b>Strategic direction 1.5: Create a culture of networking and facilitate team approach for delivery of childhood and adolescent cancer care extending from specialized centres to secondary and primary care</b>							
1.5.1 Establish a network connecting the national, provincial cancer treatment centres and other relevant hospitals & professionals for updates and experience sharing for diagnosis, treatment and follow up childhood and adolescent cancers.	Identify the stakeholders to establish network for childhood and adolescent cancer care	TAC on Childhood & Adolescent Cancer, DDG-MS 1, Director - National Cancer Institute, Director - NCCP		X	X	X	X
	Facilitate the established network to function			X	X	X	X
1.5.2 Facilitate Multi-Disciplinary Team (MDT) approach for all aspects (diagnosis, treatment, rehabilitation, survivorship care, palliative care) of childhood and adolescent cancer care	Develop Terms of Reference for Multidisciplinary team approach for Childhood and adolescent cancers	TAC on Childhood & Adolescent Cancer, DDG-MS 1, Director - National Cancer Institute, Director - NCCP		X			
	Facilitate the institutionalization of MDT approach according to the need			X	X	X	X

**Strategic Objective 2: Strengthen timely and accurate diagnostic facilities for childhood and adolescent cancers**

<b>Strategic Direction 2.1: Facilitate the process of diagnosis of childhood and adolescent cancers through multidisciplinary approach</b>							
<b>Major Activities</b>	<b>Sub activities</b>	<b>Responsibility</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024</b>	<b>2025</b>
2.1.1 Conduct regular refresher programmes for general Paediatricians on diagnosis of Paediatric and adolescent cancers	Conduct regular refresher programmes for general Paediatricians through zoom session or at the annual academic sessions of Professional Colleges	TAC on Childhood & Adolescent Cancer, Professional Colleges		X	X	X	X
	Develop a web-based update on childhood cancers targeting consultant Paediatricians			X	X	X	X
2.1.2 Conduct regular refresher programmes and introduce interactive distant learning module for primary care medical officers /general practitioners on Paediatric & adolescent cancers	Conduct regular refresher programmes for primary care medical office general practitioners through zoom session or at the annual academic sessions of Professional Colleges	TAC on Childhood & Adolescent Cancer, Professional Colleges		X	X	X	X
	Develop interactive distant learning modules on early diagnosis of childhood and adolescent cancers			X	X	X	X
2.1.3 Empower parents and teachers on early suspicious symptoms of cancers through appropriate messages without creating fear psychosis	Identify contents on early suspicious symptoms targeting civil society (parents, teachers) on early diagnosis of childhood cancers	TAC on Childhood & Adolescent Cancer, Professional Colleges		X			
	Conduct awareness programmes on early suspicious symptoms of cancers using appropriate communication materials			X	X	X	X
	Partnership with civil society organizations for conducting awareness programmes at national & regional level			X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
2.1.4 Create an updated proforma for reporting childhood and adolescent cancers to ensure uniformity of reporting	Develop guideline for uniform reporting system for diagnosis of cancers	TAC on Childhood & Adolescent Cancer, Professional Colleges		X	X	X	X
	Introduce updated uniform reporting of cancers phased out manner						
2.1.5 Establish networked laboratory reporting system for sharing patient and tumour information	Develop an IT system between NCISL, LRH, SBCH to review diagnostic reports	Director - Health Information, Director - NCISL, Director LRH, Director SBCH		X	X	X	X
	Expand network to other leading hospitals involving in diagnosis of Paediatric cancers						
2.1.6 Facilitate multidisciplinary approach including Tumour boards in diagnosis of childhood and adolescent cancer	Establish Tumour boards in diagnosis of childhood and adolescent cancer initially at NCISL & LRH	Director - Health Information, Director – NCISL		X	X	X	X
	Scaling up multidisciplinary approaches to other hospitals in phased manner	Director LRH, Director SBCH, Professional colleges		X	X	X	X
2.1.7 Ensure follow up mechanism for children with cancer predisposing syndromes at Paediatric units	Conduct capacity building programmes on cancer predisposing syndromes	Director - LRH, Professional Colleges		X	X	X	X
	Establish a register at selected Padiatric clinics to follow up of children with cancer predisposing syndromes			X	X	X	X
<b>Strategic direction 2.2: Strengthen histopathology laboratory services for diagnosis of childhood and adolescent cancers</b>							
2.2.1 Develop and implement guidelines for procedure manuals in histopathology laboratory services for diagnosis of childhood and adolescent cancers.	Develop service stratified guidelines for histopathology laboratory diagnostic procedures for diagnosis of childhood cancers.	Director- Laboratory Services, Professional Colleges		X	X	X	X
	Publish the guidelines and implement the guidelines at the laboratories in phased out manner				X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
2.2.2 Establish immunohistochemistry laboratory facilities at the specialized Paediatric hospitals (LRH-Colombo and SBCH-Peradeniya) with human resources, equipment and continuous supply of consumables including reagents for diagnosis of childhood and adolescent cancers.	Identify list of equipments, reagents and human resources to commence Immunohistochemistry facilities at LRH and SBCH in a phased manner.	Director - LRH, Director-SBCH, Director - Laboratory Services, Director- Medical Supplies Division		X			
	Identify funding sources for capital cost & recurrent costs commence IHC services			X	X	X	X
2.2.3 Establish a mechanism to review and report the Paediatric pathology samples by Pathologists at centers where Paediatric tumours are commonly seen.	Developing a mechanism in collaboration with College of Pathologists to review Paediatric pathology samples by Pathologists at centers where Paediatric tumours are commonly seen.	Director - LRH, Director Laboratory Services, College of Pathologists		X	X	X	X
	Regular refresher programmes on diagnosis of Paediatric pathology samples with the participation of national & international experts			X	X	X	X
2.2.4 Provide special training for Pathologists prior to taking up posts in Paediatric hospitals.	Develop a structured in-service training module for pathologists assuming duties at Paediatric hospitals	Director - LRH, Director Laboratory Services, College of Pathologists		X	X	X	X
	Conduct in service training programmes for Pathologists at the LRH						
<b>Strategic direction 2.3: Strengthen Haematology laboratory services for diagnosis of childhood and adolescent cancers</b>							
2.3.1 Ensure availability of flow cytometry facilities at the hospitals with Pediatric cancer units and Lady Ridgeway Hospital	Conduct need assessment for flow cytometry for Paediatric malignancies	Director Laboratory Services, College of Haematologists		X			
	Allocating funds for procuring flow cytometry facilities to hospitals with Pediatric cancer units and Lady Ridgeway Hospital			X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
2.3.2 Ensure regular supply of reagents for Minimal Residual Disease (MRD) analysis for Leukaemia	Develop protocols for MRD analysis	Director- NCISL Hospital, Director- MSD, College of Haematologists		X			
	Estimate supply of reagents and ensure regular supply of reagents for MRD Analysis			X	X	X	X
2.3.3. Develop guidelines on Haematological diagnosis and follow up for childhood and adolescent cancers and ensure implementation	Develop service stratified guidelines for diagnosis of hematological malignancies in childhood	Director Laboratory Services, College of Hematologists		X			
	Implementation of guidelines at the Haematological laboratories			X	X	X	X
2.3.4 Provide regular training to the Haematology staff on diagnosis of childhood and adolescent cancer.	Conduct in service training programmes for the Haematology staff on diagnosis of childhood and adolescent cancer	Director - Laboratory services, College of Haematologists		X	X	X	X
	Coordinate with national and international experts in Haematology for updates on diagnosis of Haematological malignancies in childhood				X	X	X
2.3.5 Allocate at least one machine for the country as a national reference centre for RT - PCR at CISL	Procurement of RT-PCR machine as a national reference centre for diagnosis of Haematological malignancies	Director - Laboratory services, College of Haematologists		X	X	X	X
<b>Strategic direction 2.4: Strengthen chemical pathology laboratory services for diagnosis of childhood and adolescent cancers</b>							
2.4.1 Ensure availability of reagents to chemical pathology laboratories for diagnosis and follow up of childhood and adolescent cancers	Advocate chemical pathology laboratory staff to update the reagent list regularly and prepare annual estimates	Director - NCISL Hospital, Director- LRH		X	X	X	X
2.4.2 Develop guidelines on chemical pathology for diagnosis and follow up for childhood and adolescent cancers.	Develop guidelines on chemical pathology for diagnosis and follow up on malignancies in childhood	Director- Laboratory Services, College of Chemical Pathologists		X	X	X	X
	Implementation of guidelines at the chemical pathology laboratories			X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
2.4.3 Provide a special training to the chemical pathology staff on diagnosis of childhood and adolescent cancer	Conduct capacity building programmes to the chemical pathology staff on diagnosis and follow of childhood and adolescent cancer	Director- Laboratory Services, College of Chemical Pathologists		X	X	X	X
<b>Strategic direction 2.5 Strengthen molecular &amp; genetic testing facilities for diagnosis of childhood and adolescent cancer</b>							
2.5.1 Establish molecular, cytogenetics and genetic testing facilities at National Cancer Institute of Sri Lanka	Major activity 4.2.4.3 of NSP on Prevention & Control of Cancers 2020-2024	National Advisory Committee on Prevention & Control of Cancers, DDG (LS), DDG (MS 1), Director-NCISL		X	X	X	X
2.5.2 Ensure availability of relevant technical staff including laboratory technicians, bioinformatician, clinical geneticist, genetic diagnostic technicians, scientists and molecular biologists.	Create cadre positions and appoint the technical staff at molecular and genetic lab	DDG (LS), DDG- Planning			X	X	X
2.5.3 Develop national genetic diagnostic guidelines and protocols for Childhood and adolescent cancers	Develop national genetic diagnostic guidelines and protocol for childhood and adolescent cancers in phased out manner	TAC on Childhood & Adolescent Cancers, Professional Colleges			X	X	X
<b>Strategic direction 2.6: Strengthen radiological services for diagnosis of childhood and adolescent cancers</b>							
2.6.1 Ensure facilities (Anesthetist, anesthetic machine) to conduct PET/ CT under general anesthesia at National Cancer Institute of Sri Lanka	Provision of facilities to conduct PET/ CT under general anesthesia at NCISL	Director -NCISL	X				
2.6.2 Establish PACS system for sharing patient information within and between hospitals. (Connecting LRH and NCISL).	Ensure to supply all the infrastructure, multimedia devices and human resources required to develop PACS system	Director- NCISL, Director-LRH, Director - Information		X			
	Provide an in-service training for the staff to operate and maintain the system			X	X	X	X



Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
2.6.3 Ensure 3 D MRI facility at National Cancer Institute OF Sri Lanka minimizing transferring patient to other hospitals for MRI	Procurement of 3 D MRI to NCISL	DDG (BME)		X			
2.6.4 Provision of PET CT/ PET MRI to LRH	Procurement of PET CT/ PET MRI to LRH	DDG (BME)		X			
2.6.5 Appoint interventional Radiologists /Paediatric Radiologists to main Paediatric hospitals / teaching hospitals / Provincial General hospitals ensuring access to biopsies of Pediatric solid tumors	Appointment of Paediatric Radiologist to Teaching hospital in phased out manner according to prioritized order	DDG (MS 1), DDG Planning, TAC on Childhood Adolescent Cancers		X			
2.6.6 Ensure good X-rays/ good USS for secondary and tertiary care hospital facilitating early diagnosis	Regular update on Paediatric cancers to consultant Radiologists	Professional Colleges		X	X	X	X
	Provision of quality X ray and USS to hospitals enabling early detection of Paediatric cancers	DDG (BME)		X	X	X	X

### Strategic objective:3 Ensure timely and accurate diagnosis of childhood and adolescent cancers in Sri Lanka

#### Strategic direction 3.1- Develop the National Cancer Institute of Sri Lanka as the centre of excellence for childhood and adolescent cancer care in Sri Lanka

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.1.1 Strengthen existing Paediatric Cancer Treatment Unit at National Cancer Institute Maharagama incorporating essential services for provision of comprehensive care	Identify and provide essential infrastructure needs of existing Paediatric cancer treatment unit	Director - NCISL, DDG (Medical Services 1),	X	X	X	X	X
	Identify human resource needs (Medical officers, nursing officers .....etc) and appoint to ensure quality care	Director - NCISL, DDG (Planning), DDG (MS II), Director- Nursing (Medical Services), DDG (Administration 1)	X	X	X	X	X
	Promote multidisciplinary care approach for Paediatric cancer care	Director - NCISL	X	X	X	X	X
3.1.2 Expedite the construction of proposed Childhood and adolescent cancer care unit (including modern Paediatric cancer care unit including separate sub units for adolescent cancer patients, ICU and HDU.... etc) ( <i>Razavi Project II</i> )	Review the current progress of activities and identify necessary actions to proceed	Director -NCISL, DDG (Planning),	X	X			
	Communicate with External Resource Department of Ministry of Finance and expedite the process in identifying international partnership for the project	DDG (Planning)			X	X	X
3.1.3 Facilitate liaising of National Cancer Institute of Sri Lanka with Childhood Cancer Care Network (CCN) of WHO Global Initiative for Childhood Cancer Care to promote connected and integrated cancer care improvement	Conduct regular meetings with national stakeholders including National Cancer Institute, National Cancer Control Programme, Professional Colleges and WHO country office to identify future actions	Director – NCISL & Focal Point for WHO Childhood Cancer Care Network	X	X			

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
	Brief the progress to the TAC on Childhood & Adolescent Cancer to facilitate the progress		X	X	X	X	X
3.1.4 Facilitate liaising of National Cancer Institute of Sri Lanka with international collaborators such as St. Jude Global Alliance (SGJA) of St. Jude Hospital for Paediatric cancers in USA to promote a connected and integrated cancer care improvement	Conduct regular meetings with national stakeholders including National Cancer Institute, National Cancer Control Programme, Professional Colleges and SJGA to identify future actions	Director - NCISL & Focal Point for SJGA	X	X			
	Brief the progress to the TAC on Childhood & Adolescent Cancer to facilitate the progress		X	X	X	X	X
3.1.5 Establish telemedicine facilities for cancer care including follow up care with other cancer treatment centres and main hospitals (4.5.4 of NSP 2020 -2024)	Conduct a pilot study to determine the cost-effectiveness of telemedicine services for Paediatric cancer.	DDG (MS 1), DDG ET & R, Director - NCISL, Director - Information	X	X			
	Review the current progress of activities and identify necessary actions to scale up			X	X		
	Scale up the telemedicine facilities through the provision of necessary infrastructure				X	X	X

<b>Strategic direction 3.2: Strengthen childhood and adolescent cancer care at the identified cancer treatment centres in the country in equitable manner</b>							
<b>Major Activities</b>	<b>Sub activities</b>	<b>Responsibility</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024</b>	<b>2025</b>
3.2.1 Scale up dedicated Paediatric Oncology services at NH Kandy, TH Karapitiya, BH Telippalai (TH Jaffna), TH Batticaloa in a phased manner to ensure equitable access to Paediatric cancer care (Activity 4.5.1 of National Strategic Plan on Prevention & Control of Cancers 2020 - 2024)	Advocate appointment of Paediatric Oncologists to NH-Kandy, TH-Karapitiya, TH Anuradhapura and TH-Jaffna in a phased manner with development of infrastructure and resources.	DDG (MS 1), DDG (Planning)			X	X	X
3.2.2 Strengthen up providing facilities in already established Oncology units for care of these patients	Encourage and facilitate MDT based decision making	DDG- Planning, DDG-MSD, Director- NCISL, LRH and other hospitals		X	X	X	X
	Provide required infrastructure and human resources			X	X	X	X
	Develop a network/ referral system in liaising the peripheral Oncology units with the particular central centers.			X	X	X	X
<b>Strategic direction 3.3: Strengthen comprehensive care for childhood and adolescent cancer patients at the identified cancer treatment centres</b>							
3.3.1 Develop & introduce guidelines/protocols /SOPs for management of childhood and adolescent cancer care (4.5.2 of NSP on Prevention & Control of Cancers 2020 - 2024)	List & prioritize resource stratified guidelines/ protocols/SOPS for management of childhood and adolescent cancer care	TAC on Childhood & Adolescent Cancer, Professional Colleges	X	X			
	Develop resource stratified guidelines/ protocols/SOPS for management of childhood and adolescent cancer care		X	X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.3.2 Encourage and facilitate multi-disciplinary team based (MDT) decision making at least for the complicated cases of childhood and adolescent cancers	Develop Terms of Reference (TOR) for the MDT	TAC on Childhood & Adolescent Cancer, Professional Colleges	X	X			
	Identify necessary resources and provision of those to commence MDT	Director - NCISL		X			
	Conduct regular MDT Sessions and regular review for further update the format	Director - NCISL, Professional Colleges, TAC on Childhood & Adolescent Cancer		X	X	X	X
3.3.3 Introduce Paediatric cancer early warning system (PEWS) and train the health care team to detect early sepsis and organ dysfunction to improve overall outcomes of children with cancer	Develop a training need assessment plan for the health care teams	Director - NCISL, Directorate of Health Care Quality, Professional Colleges		X	X		
	Conduct in- service training programmes for the health care team regarding early detection of sepsis.			X	X		
	Develop and validate a tool for PEWS in Sri Lankan setting.			X	X		
	Conduct a pilot study to evaluate cost- benefit of PEWS			X	X	X	
	Integrate PEWS to the routine Paediatric cancer care					X	X
3.3.4 Expand day care treatment facilities for Paediatric and adolescent cancer patients	Identify resources to expand day care treatment facilities	Director - NCISL		X			
	Expand day care facilities with physical and human resources			X	X		
	Develop clinical protocols and regular service audit				X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.3.5 Improve access to supportive care facilities including nutrition, growth and development as well as other general Paediatric care needs in children and adolescents with cancers	Determine the role of Consultant Paediatrician as a team member of provision of care for childhood cancers and provide necessary physical resources to further facilitate Paediatric Oncology care.	Director - NCISL, TAC on Childhood & Adolescent Cancer	X	X	X	X	X
	Commence regular general Paediatric clinic to follow up growth, nutrition and development and other Paediatric care needs at National Cancer Institute of Sri Lanka	Director - NCISL,		X	X	X	X
3.3.6 Improve measures to minimize cross infections among childhood & adolescent cancer patients at hospital setting	Provide all infrastructure and human resources required for infection control at the Paediatric Oncology unit	Director - NCISL & Consultant Microbiologist, Consultant Virologist	X	X			
	Develop childhood cancer specific guidelines/ protocols on infection control			X	X		
	Conduct CPD sessions on infection control for all health care staff.			X	X	X	X
	Educate parents and caregivers on infection control			X	X	X	X
3.3.7 Develop and implement in-service training modules including hands on training for newly appointed medical officers for the Paediatric Oncology units	Develop a structured in-service training module for newly appointed medical for the Paediatric Oncology Units	Director- NCISL, Consultant Paediatric Oncologists	X	X			
	Conduct in service training programme at least twice a year for the Medical Officers at the Paediatric oncology Units			X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.3.8 Develop and implement in-service training programme for nursing staff at the Paediatric Oncology Units	Develop in service training programme for nursing staff at the Paediatric Oncology Units	Director- NCISL Consultant Paediatric Oncologists, Chief Nursing Officer	X	X			
	Conduct in service training programme for nursing staff at the Paediatric Oncology Units			X	X	X	X
3.3.9 Establish Clinical nutrition unit and availability of nutrition support at any given time.	Advocate appointment of Consultant Clinical Nutritionist to National Cancer Institute and further strengthen nutrition follow up	DDG(MS1), Director - NCISL	X	X			
	Commence clinical nutrition unit at NCISL and ensure availability of services for children and adolescents with cancers at any given time			X	X	X	X
<b>Strategic direction 3.4: Improve care at the intensive care units and emergency treatment units for critically ill childhood and adolescent cancer patients</b>							
3.4.1 Assess the needs of intensive care facilities affiliated to Paediatric Oncology units and improve the facilities according to the need	Conduct situation analysis of use of intensive care facilities for Paediatric Oncology care and identify further needs	Director - NCISL, Consultants at Paediatric Oncology Unit		X			
	Provision of required facilities for further strengthening intensive care facilities			X	X	X	X
3.4.2 Develop and implement guidelines for management of Paediatric cancer patients admitted to emergency treatment units for early identification and relevant interventions for Oncological emergencies (eg. Febrile neutropenia, Tumour lysis syndrome ... etc)	Review of Paediatric cancer emergencies admitted to Paediatric Oncology units and other emergency treatment units at major hospitals	Director – NCISL, TAC on Childhood & Adolescent Cancer		X			
	Develop & implement guidelines for management Paediatric Oncology emergencies			X	X	X	X

<b>Strategic direction 3.5 Ensure availability of quality assured medicines in appropriate strengths and dosage forms for childhood and adolescent cancer care</b>							
<b>Major Activities</b>	<b>Sub activities</b>	<b>Responsibility</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024</b>	<b>2025</b>
3.5.1 Develop a National Essential Medicine List (NEML) for Paediatric Oncology to ensure availability of essential Paediatric Oncology medicines without stock-out situations in appropriate strengths and dosage forms.	Develop National Essential Medicine list for Paediatric Oncology	NMRA, Director MSD, Professional Colleges		X			
	Ensure availability of Paediatric oncology drugs in appropriate strengths and dosage forms			X	X	X	X
	Inclusion of new drugs to National Essential Medicine List after Health Technology Assessment					X	X
3.5.2 Strengthen the existing mechanism to monitor the needs, the volumes received and volumes utilized, periods of stock-out situations ..... etc to ensure continuous delivery of medicines in appropriate strengths and dosage forms in collaboration with Medical Supplies Division (MSD).	Further strengthening of monitoring mechanism of supply chain of Paediatric Oncology drugs	Director - MSD, Director- NCISL Directors of other hospitals		X	X	X	X
	Review of status of Paediatric oncology drugs at every Technical Advisory Committee meeting			X	X	X	X
3.5.3 Develop and implement a sustainable quality assurance mechanism to ensure availability of good quality medicines for Paediatric Oncology care	Develop & implement quality assurance mechanism for Paediatric oncology drugs networking with Clinicians, Clinical Pharmacologists and National Drug Quality Assurance Laboratory (NDQAL)	NDQAL, MSD		X	X		
	Regular review of the quality of the Paediatric oncology medicines at hospital level	Director- NCISL			X	X	X



Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.5.4 Enhance good distribution practices and storage of Paediatric cancer drugs at the Paediatric cancer treatment centres	Develop Standard Operational Procedures for good distribution practices and storage of Paediatric cancer drugs	Director- NCISL, Director MSD		X	X	X	X
	Implement institutional arrangements to enhance good distribution practices and storage of Paediatric cancer drugs			X	X	X	X
3.5.5 Ensure special allocation of funds at the Ministry of Health and at the cancer treatment centres to purchase drugs locally that are not available under special circumstances with the concurrence of National Medicines Regulatory Authority (NMRA ).	Explore the possibility of reserving special allocation of funds annually at the Ministry of Health and at the cancer treatment centres to purchase drugs locally that are not available under special circumstances with the concurrence of National Medicines Regulatory Authority (NMRA ).	Director - MSD, Director-NCISL, NMRA		X	X	X	X
	Annual review of utilization of funds for local purchase of drugs for Paediatric cancer care			X	X	X	X
3.5.6 Develop a network for Paediatric Oncology medicine users to monitor safety of the medicines and offer pharmacovigilance services in collaboration with NMRA.	Develop a mechanism to monitor safety and adverse effects of Paediatric Oncology medicine	Director - MSD, Director- NCISL, NMRA, Drug Information Centre- University of Colombo		X	X	X	X
	Annual review pharmacovigilance for Paediatric Oncology medicines			X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.5.7 Establish a mechanism to purchase the non -formulary drugs whenever needed for rare childhood cancers	Develop a mechanism to purchase the non -formulary drugs whenever needed for rare childhood cancers	Director - MSD, Director-NCISL, NMRA		X	X	X	X
	Annual review of utilization of funds to purchase the non -formulary drugs whenever needed for rare childhood cancers			X	X	X	X
3.5.8 Ensure provision of therapeutic nutrition for needy Paediatric cancer patients	Monitor the therapeutic nutrition needs of Paediatric cancer patients	Director- NCISL		X			
	Availability of essential therapeutic nutrition products at Paediatric oncology units according to the need			X	X	X	X
3.5.9 Advocate for appointment of Clinical Pharmacologist to NCISL & establishing clinical pharmacology unit	Request for carder approval for a Clinical Pharmacologist to NCISL	Director- NCISL		X			
	Develop a term of reference for a clinical pharmacology unit and obtain formal approval				X	X	X
3.5.10 Further strengthen the mechanism to obtain civil society support for provision of drugs for Paediatric cancer patients	Establish the mechanism to obtain the civil society participation for provision of drugs for Paediatric cancer patients	Director- NCISL		X			
	Conduct annual review of civil society participation for provision of drugs for Paediatric cancer patients			X	X	X	X

**Strategic direction 3.6: Strengthen surgical care for childhood and adolescent cancer care**

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.6.1 Link Paediatric surgical care services (Paediatric surgery, Surgical sub specialties – Orthopedics, Neurosurgery, Ophthalmology, ENT surgery, Oncosurgery, Thoracic surgery) with the Paediatric Oncology services, pathology services and Radiology services	Strengthening communication links between Paediatric surgical specialties with the Paediatric Oncologists, Pathologists & Radiologists	Director- LRH, Director-NCISL, Director SBCH,	X	X	X	X	X
	Facilitate Tumour boards & multidisciplinary team meetings between different specialties			X	X	X	X
3.6.2 Conduct situation analysis of surgical care needs for childhood and adolescent cancers throughout the country and prioritize interventions	Conduct situational analysis and identify surgical care needs for childhood and adolescent cancers including human resource & physical resource throughout the country and prepare prioritized plan	TAC on Childhood & Adolescent Cancers, College of Surgeons, Association of Paediatric Surgeons, WHO Childhood Cancer Project		X			
	Ensure provision of identified needs in phased out manner				X	X	X
3.6.3 Strengthen Paediatric surgical units (Paediatric surgery, Surgical sub specialties – Orthopaedics, Neurosurgery, Ophthalmology, ENT surgery ..... ) at Lady Ridgeway Hospital for advanced surgical management of Pediatric cancers	Inclusion of identified needs of expansion of advanced surgical management of different Paediatric surgery sub specialties and include to the Master Plan of the LRH to be implemented	Director - LRH, Consultant Paediatric Surgeons & Consultants in Other Surgical Specialties		X			
	Ensure provision of identified needs ( eg. Surgical theatre time, bed strength, equipment..... ) in prioritized manner			X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.6.4 Ensure availability of surgical products needed for treating of childhood cancers (venous access devices, surgical instruments including bone marrow needles, Paediatric orthopedic bone tumour instruments, implants) – mega prostheses	Updating the need of surgical instruments needed for Paediatric cancer surgeries	Director MSD, Director-LRH, Director - SBCH		X			
	Ensure provision of identified needs in phased out manner			X	X	X	X
3.6.5 Facilitate clinical audits at the Paediatric surgical units on Childhood and Adolescent Cancer Care	Develop relevant protocols for conducting clinical audits	Director-LRH, Director - SBCH, Consultants		X			
	Perform regular clinical audits for continuous quality improvement process.			X	X	X	X
3.6.6 Networking with a International Paediatric surgical care network further enhancement of Childhood and Adolescent Cancer Care	Explore the possibility of joining for an international Paediatric care network	WHO Childhood cancer project, Professional Colleges		X			
	Facilitate knowledge sharing sessions - Virtual sessions, Skill building workshops etc			X	X	X	X
<b>Strategic direction 3.7: Strengthen radiotherapy facilities for childhood and adolescent cancer care</b>							
3.7.1 Ensure access to quality radiotherapy services for all children who need this modality by having dedicated radiotherapy slots	Inclusion of radiotherapy needs for childhood and adolescent cancer patients to the proposed strategic plan on radiotherapy development	TAC on Diagnoses & Treatment, TAC on Childhood & Adolescent Cancers, College of Oncologists		X	X		
	Implementation of identified actions in phased manner				X	X	X
3.7.2 Establish teams consisting of Consultants, Medical officers, physicists, therapy radiographers, nurses, support	Identify the teams needed for the provision of quality radiotherapy for childhood cancer patients	Director- NCISL, Director - Health Care Quality & Safety,		X			

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
staff trained in handling children needing Radiotherapy.	Provision of regular in-service training including patient preparation, Radiotherapy safety measures and follow up care	Atomic Energy Authority		X	X	X	X
3.7.3 Ensure adequate anesthetic support for children needing radiotherapy.	Provision of anesthetic facilities for children who need radiotherapy	Director- NCISL		X			
3.7.4 Ensure availability of Paediatric size immobilization devices, applicators, molds for radiotherapy for children and adolescents with cancer	Provision of Paediatric size immobilization devices, applicators, molds for radiotherapy for children and adolescents with cancer	Director-NCISL		X			
3.7.5 Networking with Paediatric radiotherapy professional group for enhancement of radiotherapy care	Joining with an international professional group for enhancement of radiotherapy care	WHO Cancer Care Network, St. Jude Global Alliance, IAEA		X			
<b>Strategic direction 3.8: Strengthen microbiological services for childhood and adolescent cancer care</b>							
3.8.1 Strengthen microbiology services for early diagnosis of sepsis among children and adolescents with cancers	Provide all the devices, reagents, infrastructure required for microbiology testing services.	Director- NCISL, Consultant Microbiologist at		X	X		

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
	Develop guidelines and protocols for early diagnosis of sepsis	NCISL		X			
	Conduct microbiology training programmes for Childhood and adolescent cancer care staff for early diagnosis of sepsis among childhood and adolescent cancer patients			X	X	X	X
3.8.2 Minimize disruption to childhood cancer care due to Covid 19 pandemic	Ensure availability of PCR testing kits, PPE and laboratory facilities at cancer treatment centers.	Director- NCISL, Consultant Microbiologist at NCISL		X	X	X	X
	Improve access to childhood and adolescent cancer care minimizing delays in screening for Covid -19)			X	X	X	X
3.8.3 Development and implementation of anti-microbial stewardship programme for minimizing antimicrobial resistance	Develop Standard Operational Procedures to minimize anti microbiological resistance	Director-NCISL, Consultant Microbiologist at NCISL	X	X			
	Training of infection control practices Paediatric Oncology unit staff		X	X	X	X	X
<b>Strategic direction 3.9 : Commence of advanced treatment options for childhood and adolescent cancer care</b>							
Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.9.1 Establish stem-cell transplantation (both autologous & allogenic) programme for Pediatric cancer care at the National Cancer Institute, Sri Lanka	Identify the team leader and stem cell transplant team.	Director -NCISL		X			
	Identify the package of diagnostics, infrastructure and human resources needed for autologous and	Director- NCISL, Team leader of stem cell transplant		X	X		

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
	analogous stem cell transplant	programme and professional colleges					
	Develop Standard Operational Procedures (SOPs) for establishing stem cell transplantation for Paediatric cancer care			X	X		
	Allocation of funds and procurement of necessary equipment for stem cell transplant			X	X	X	X
3.9.2 Create special training programmes for medical officers, nursing officers and other relevant staff to initiate stem cell transplantation for childhood cancers.	Develop training programmes for staff categories including medical officers and nursing officers after identifying the training requirements.	Director - NCISL	X	X	X	X	X
	Conduct tailor made training programmes for stem cell transplant team				X	X	X
<b>Strategic direction 3.10: Introduce total pain free procedures for the treatment of childhood and adolescent cancer care</b>							
Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.10.1 Establish pain free procedures at Paediatric Oncology units	Identify devices and consumables required to commence pain free procedures.	Director - NCISL		X	X		
	Provide devices and consumables required to commence pain free procedures.				X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.10.2 Ensure minimal side effects and discomfort due to Paediatric cannulation	Provide specialized training for health care team on Paediatric cannulation for childhood cancer patients	Director - NCISL	X	X	X		
3.10.3 Establish a procedure room per ward for each Paediatric Oncology unit	Establish procedure room per ward for each Paediatric Oncology unit	Director - NCISL, Director LRH, Director SBCH		X	X		
	Ensure a continuous supply of consumables to these procedures rooms			X	X	X	X
3.10.4 Appoint a designated "pain team" including a Consultant Anesthetist at each Paediatric Oncology Centre	Establish a "pain team" in each childhood cancer treatment centre	Director - NCISL, Director LRH, Director SBCH		X	X		
	Identify role of Pain team in minimizing pain among Paediatric cancer patients and implement at each childhood cancer centre				x	x	x
<b>Strategic direction 3.11: Address to specific psycho- social and spiritual needs of children and adolescents with cancer</b>							
Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.11.1 Develop a mechanism to address to psychosocial needs of childhood and adolescent cancer patients and their family members	Arrangement of services of a Child & Adolescent Psychiatrist for childhood and adolescent cancer patients and their family members	Director -NCISL, Director LRH, Director SBCH		X	X	X	X
	Train Medical Officers and Nursing Officers to identify and address psychosocial needs of childhood and adolescent cancer patients and their family members			X	X	X	X



Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
	Arrangement of a dedicated social worker to address the social needs of childhood and adolescent cancer patients and their family members	Director - Social Services Department (Line Ministry / Provincial)		X	X	X	X
3.11.2 Develop mechanism to ensure continuity of school education while the child is receiving inward care	Establish "Sathi Pasala" with dedicated school teachers adjacent to Paediatric Oncology units	Director -NCISL, Director - Health & Nutrition of Ministry of Education		X	X	X	X
	Strengthen library facilities at each cancer treatment centre			X	X	X	X
3.11.3 Establish a family room for family meetings (eg. Breaking serious news) at Paediatric oncology treatment units and other diagnostic centers.	Establish family room for family meetings attached to Paediatric oncology units	Director -NCISL, Director LRH, Director SBCH		X	X	X	X
3.11.4 Establish parent support groups to continue the journey with the affected child	Establish parent support groups at each Oncology unit with the guidance of hospital director	Director - NCISL, Director LRH, Director SBCH, Social Services Officer, Civil Society Organizations		X	X	X	X
3.11.5 Establish peer support groups/Bravery groups	Establish peer support groups / bravery groups affiliated to Paediatric Oncology	Director - NCISL, Director LRH, Director SBCH, Social Services Officer, Civil Society Organizations		X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
3.11.6 Strengthen the community care and home care linking primary health care teams	Develop a shared care plan to communicate with primary health care and community	Director - NCISL		X			
	Piloting the shared care plan in selected districts				X		
	Modify and scale up shared care plan after pilot test					X	X
3.11.7 Develop partnerships with other government and non-government organizations to ensure extended support for children and adolescents with cancers	Introduce recreational activities to affected children - Music, Art, drama..... Etc	Director -NCISL, Director LRH, Director SBCH, Social Services Officer, Civil Society Organizations		X	X	X	X

## Strategic Objective 4 : Ensure access to rehabilitation, long-term survivorship care and community reintegration of patients with childhood and adolescent cancers

Strategic direction 4.1: Access to counselling services for the patients with childhood and adolescent cancers and their families							
Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
4.1.1 Strengthen specially trained counselling team at National Cancer Institute, Sri Lanka (NCI SL) and Lady Ridgeway Hospital for Children (LRH) for the patients with childhood & adolescent cancers	Identify a focal point for coordinating the counselling service	Director-NCI SL, Director -LRH, Consultant Psychiatrists at NCI SL & LRH, Director - Mental Health, Director -NCCP		X			
	Identify a “Counselling team” and arrange special training programme to attend to the counselling needs of patients with childhood & adolescent cancers and their care givers			X			
	Provision of space and other facilities for commencing dedicated counselling service			X			
	Establish the counselling service at NCISL & LRH			X	X	X	X
4.1.2 Design and implement formal training programmes on basics of communication and counselling for the medical, nursing staff and other categories of staff working at the Paediatric cancer units	Conduct in service training programmes on basics of communication and counselling for the health staff	Director-NCISL, Director -LRH, Consultant Psychiatrists at NCISL & LRH, Hospital Counselling team - NCI SL & LRH		X	X	X	X
	Develop training modules on the basics of communication and counselling for the health care categories					X	X
4.1.3 Establish specially trained counselling teams at the relevant hospitals where the childhood & adolescent cancer patients are being diagnosed and/or treated. (These counselling teams need to provide	Identify existing “counselling teams” at the hospitals and arrange special training programme to attend to the counselling needs of patients with childhood & adolescent cancers and their care givers	Directors of the hospitals, Consultant Psychiatrist in the hospitals, Director - Mental Health		X	X	X	X

Major Activities	Subactivities	Responsibility	2021	2022	2023	2024	2025
services to Paediatric Surgical units, Neuro surgical Units, Orthopaedic units, ENT units, Ophthalmology units in addition to the oncology units when needs arise)	Conduct regular refresher training programmes and experience sharing sessions with established counselling team at Paediatric Oncology unit at National Cancer Institute of Sri Lanka				X	X	X
<b>Strategic direction 4.2: Ensure access to rehabilitation services for childhood and adolescent cancers</b>							
4.2.1 Strengthen provision of services for the rehabilitation needs of patients with childhood and adolescent cancers	Identify a focal point for coordination of rehabilitation services for childhood and adolescent cancers at NCI SL	Director-NCI SL, Consultant Paediatric Oncologists & Consultant Paediatrician at the National Cancer Institute		X			
	Document rehabilitation needs of patients with childhood and adolescent cancers			X			
	Identify the resources and map the resources			X			
	Provide specialized rehabilitation training and improve capacity building of the health care teams at the Paediatric Oncology Unit at the National Cancer Institute of Sri Lanka			X	X	X	X
4.2.2. Commence dedicated rehabilitation clinic service for the survivors of childhood and adolescent cancers	Establish a rehabilitation clinic service led by relevant specialties. Eg: Consultant Paediatrician, Consultant Rheumatologist & Rehabilitation Physician, etc.	Director-NCI SL, Consultant Paediatric Oncologists & Consultant Paediatrician at NCISL		X	X	X	X
4.2.3 Refresher training for physiotherapists, occupational therapists and speech therapists in relation to provision of services for the survivors of childhood and adolescent cancers	Prepare in service training programmes for physiotherapists, occupational therapists and speech therapists	Director-NCISL, Director - Training,		X			
	Conduct regular refresher training programmes			X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
4.2.4 Networking with other stakeholders for provision of rehabilitation services.	List other stakeholders for provision of rehabilitation for Childhood & Adolescent Cancer Patients	Director-NCISL, Director - NCCP, Director - YEDD, Director - MCH, Director -PHSD Director – Social Services		X			
	Develop linkages with Paediatric oncology unit to facilitate provision of services in coordinated manner				X	X	X
<b>Strategic direction 4.3: Ensure long term survivorship care for childhood and adolescent cancers</b>							
Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
4.3.1 Strengthen Paediatric cancer survivorship care programme (physical, psychological, social, spiritual) at NCI SL for the patients with childhood and adolescent cancers.	Identify a focal point for coordinating survivorship care programme for patients with childhood and adolescent cancers.	Director -NCISL, Consultant Paediatric Oncologists, Consultant Paediatrician at National Cancer Institute		X			
	Conduct sensitization workshops for health care workers to understand the concept of survivorship of patients with childhood and adolescent cancers.			X			
	Develop specific guidelines for long term survivorship care for childhood and adolescent cancer patients					X	X
4.3.2 Develop long term survivorship care plan for each survivor in collaboration with the child and family.	Develop person centered survivorship care plan in more qualitative way.	Consultant Paediatric Oncologists, Consultant Paediatrician at National Cancer Institute			X	X	X
4.3.3. Communicate survivorship care plan to family, primary care physician, school of the child and Social service officer, etc	Establish a mechanism to develop survivorship care plan for the childhood cancer survivors	Director -National Cancer Institute, Director - NCCP, Consultant Paediatric	X	X			
	Document survivorship care plan and communicate with family, primary care physician, , school of the child and social service officer				X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
	Identify medical officers and nursing officers attach to Paediatric Oncology unit to communicate survivor ship plan to other stakeholders according to the need	Oncologists, Consultant Paediatrician at NCISL			X	X	X
4.3.4 Strengthen follow up educational interventions for childhood and adolescent cancer survivors	Identify a focal point at the Ministry of Education to coordinate educational interventions in liaising with the hospital and school of the child	Director - Health & Nutrition of Ministry of Education		X	X	X	X
4.3.5 Establish a survivorship clinic for long-term follow up patients at Paediatric cancer units.	Conduct dedicated clinic for Paediatric cancer survivors at Paediatric cancer units						
	Establish multidisciplinary team supports at clinics	Director -NCISL, Consultant Paediatric Oncologists,			X		
	Arrange motivational programmes with survivors and their families.	Consultant Paediatrician at National Cancer Institute				X	X
	Provide assistance with transition to adult health.						X
<b>Strategic direction 4.4: Strengthen family and community empowerment for childhood and adolescent cancers</b>							
Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
4.4.1 Conduct informal care giver training programmes for family members of children and adolescents with cancers.	Arrange care giver training programmes at the Paediatric Oncology Unit	Director - NCISL, Director - NCCP	X	X	X	X	X
	Distribute IEC materials among caregivers to enhance their knowledge		X	X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
4.4.2 Empower primary care medical officers & nursing staff (including PHNOs) on follow up care for patients with childhood and adolescent cancers in the community setting	Arrange programmes to emphasis the importance survivorship care for health care staff at national level	Director - NCCP		X	X	X	X
4.4.3 Consider Paediatric cancer to be categorized as a special disease entity for funding of Social Services Department during active treatment phase.	Communicate & arrange Social Service Support	Director - NCCP, Director - Social Services Department		X	X	X	X
4.4.4 Establish a network of friends & well-wishers of Paediatric cancer unit to formalize philanthropic contributions for Paediatric cancer care	Prepare a list of NGOs, Civil society organizations and other donor institutes contributing for Childhood and adolescent cancer care	Director - NCISL		X	X	X	X
	Annual review of performance of work related to Childhood & Adolescent cancer care by the civil society				X	X	X
4.4.5 Ensure welfare of families affected by childhood cancers	Identify a coordinator linking with other government and non-government organizations for arranging welfare facilities	Director - NCISL, Director- NCCP, Director Social Services Department		X	X	X	X
	Provision of social and monitory support in coordination with Civil Society Organizations at National Level &				X	X	X
4.4.6 Establish mental health services to address psychological issues including sexual problems in adolescence cancers.	Commencement of Childhood Adolescent Mental Health Clinic service for the long term survivors	Director - NCISL, Director - Mental Health		X	X	X	X

## Strategic Objective 5: Ensure access to palliative care services to meet the needs of patients with childhood and adolescent cancers and their families

Strategic direction 5.1: Provide palliative care services for children and adolescents with cancers							
Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
5.1.1 Develop protocols related to Paediatric palliative care services	Identify needed protocols related to Paediatric palliative care services	Director- NCISL, Consultant Paediatric Oncologist & Consultant Paediatrician at the National Cancer Institute, NCCP		X	X		
	Develop protocols related to Paediatric palliative care services in a phased out manner				X	X	X
5.1.2 Form a Paediatric palliative care team at National Cancer Institute of Sri Lanka through a well-designed training programme	Identify a Paediatric palliative care team led by a consultant and team comprising of medical officers, nursing officers, physiotherapists, speech therapists..... etc at treatment centers	Director - NCISL, Director - NCCP, Professional Colleges & Associations		X	X	X	X
	Identify roles and responsibilities of each team member			X	X	X	X
	Develop an in- service training plan and conduct regular training programme for all health care staff engage in palliative care.			X	X	X	X



Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
5.1.3 Provide special training to palliative care teams in other Oncology units of the country caring for children and adolescents with cancer	Identify Paediatric palliative care teams	Director of the Hospital, Director - NCCP			X		
	Conduct regular training programme for all health care staff engage in palliative care.				X	X	X
5.1.4 Establish a dedicated facility (Eg. "rainbow rooms") for terminal care for the patients with childhood and adolescent cancers at the Paediatric Oncology units	Identify requirements and finances for establishing a dedicated facility (Rainbow rooms) for terminally care patients	Director - NCISL, Development partners, NGO & Donors				X	
	Provide all the infrastructure required for rainbow rooms					X	X
5.1.5 Develop and establish a shared care plan for palliative care services for patients with childhood and adolescent cancers according to the need	Develop a multidisciplinary shared care plan	Director - NCISL, Director - NCCP, Professional Colleges & Associations		X			
	Implement shared care plan			X	X	X	X
5.1.6 Form trained primary palliative care teams (including primary care doctors, public health nursing officers and other healthcare workers) in the community level for community-based palliative care including bereavement care according to the need liaising with the Paediatric Oncology unit	Conduct regular training programme for all health care staff engage in palliative care.	Director - NCCP, PDHS, RDHS		X	X	X	X
5.1.7 Empower caregivers to carry out home-based palliative care for patients with childhood and adolescent cancers according to the need.	Identify care giver needs of Paediatric palliative care patients	Director - NCISL, Director - NCCP		X			
	Update Paediatric cancer caregiver booklet			X			X
	Incorporate Paediatric palliative care into the Training of Trainer manual (TOT)			X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
	Conduct TOT programmes and training programmes on caregiver empowerment			X	X	X	X
5.1.8 Develop a mechanism for networking with the government and non-government institutions providing palliative care for children and adolescents	Map the public and private institutions providing palliative care	Director - NCISL, Director - NCCP		X			
	Conduct advocacy meetings with public and private institution for partnership.			X	X	X	X
5.1.9 Collaboration with civil society organizations, NGOS & volunteers for further strengthening palliative care services and supportive care Eg: Hospices for Paediatric patients, etc	List the services offered by NGOS and other partners for Paediatric palliative care patients and their families	Director -NCI SL, Director - NCCP		X	X	X	X
	Communicate the identified services to the needy patients			X	X	X	X
5.1.10 Establishment of Young Oncology care group to share experience and support with treatment related side effects, complications and compliance.	Formation young Oncology care group to share experience and identify their role	Director - NCISL, Director - NCCP					
	Provision of necessary methods of communication with newly diagnosed cancer patients						
<b>Strategic direction 5.2: Empowering health care teams and other stakeholders through education</b>							
Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
5.2.1 Incorporate Paediatric palliative care module to MD and Diploma programme in Palliative Medicine conducted by the Post Graduate Institute of Medicine	Communicate with Director PGIM to incorporate Paediatric palliative care as a section in MSc & MD Palliative care programmes	Director PGIM, Board of Study on Palliative care		X	X	X	X

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
5.2.2 Incorporate of module on Paediatric palliative care in Post basic nursing programme on palliative nursing	Incorporate Paediatric palliative care into the post basic training on palliative care nursing	DDG (ET & R), Director- Nursing (Education)		X	X	X	X
5.2.3 Incorporate Paediatric palliative care session to basic and in-service training programmes of health care staff.	Identify educational needs on Paediatric palliative care for health care workers	DDG (ET & R), Director- Nursing (Education), Director – Training		X			
	Incorporate relevant components to related to Paediatric palliative care according to the task			X	X	X	X
5.2.4 Incorporate Paediatric palliative care to the curriculum of BSc nursing degree	Conduct stakeholder consultation to identify educational needs related to Paediatric palliative care for nursing under graduates	Director - NCCP, Faculty of Nursing/ Medical Sciences/ Allied Health Sciences		X	X	X	X
	Incorporate module on Paediatric palliative care to undergraduate nursing programme			X	X	X	X
5.2.5 Public Health Nursing Officers are empowered with inputs on Paediatric palliative care inputs to act upon if need arise	Incorporate training inputs on Paediatric palliative care to the existing curriculum on PHNO training programme	DDG (ET & R), Director - NCCP,		X			
	Incorporate Paediatric palliative care components to the in-service training programmes on palliative care for PHNOS				X	X	X
5.2.6 Establish Bereavement care and funeral support mechanism	Develop bereavement care programme for families of deceased children	Director- NCISL Paediatric Palliative care team, Mental health team at NCISL		X	X	X	X
	Identify government and Non-governmental personnel for delivering bereavement care				X	X	X
	Empowerment of families thorough bereavement support services					X	X

**Strategic Objective 6: Strengthen the management information system including cancer registries and comprehensive medical records to monitor the progress and evaluate the outcomes of childhood and adolescent cancers.**

<b>Strategic direction 6.1: Strengthen cancer registries to monitor the progress and evaluate the outcomes of childhood and adolescent cancers.</b>							
<b>Major Activities</b>	<b>Sub activities</b>	<b>Responsibility</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024</b>	<b>2025</b>
6.1.1 Establish hospital-based cancer registry (HBCR) on childhood cancers in par with international standards (including treatment details, follow up details and survival data) at the National Cancer Institute, Sri Lanka (NCI SL)	Identify a focal point for coordinating HBCR on childhood cancer at NCI SL	Director- NCISL, Director – NCCP	X				
	Identify required infrastructure to commence HBCR on childhood cancer.	Director-NCISL, Focal Point for HBCR, Director -NCCP	X	X			
	Develop SOPs for initiating and maintaining HBCR		X	X			
	Ensure designated officers are available to collect, continuous, accurate, timely data to the HBCR		X	X	X	X	X
	Conduct regular Inservice training programmes for officers involved in HBCR		X	X	X	X	X
	Generate regular reports based on HBCR		X	X	X	X	X
6.1.2 Establish a mechanism to share relevant data of the HBCR on childhood cancers at the NCI SL with the National Cancer Registry Programme of Sri Lanka	Develop SOPs for sharing relevant data of the HBCR on childhood cancers to the National Cancer Registry Programme	Director-NCCP, Director - NCISL	X	X			
	Incorporate relevant data to National Cancer Registry Programme without data redundancy	Director-NCCP, Director -NCISL	X	X			

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
6.1.3 Commence Population-Based Cancer Registry of Childhood Cancers (PBCR of Childhood Cancers) in Colombo district utilizing existing population based cancer registry infrastructure and analyzing data using International Classification of Childhood Cancer, Third edition (ICCC-3) in par with global initiative of childhood cancer registries (Child GICR)	Develop SOPs on PBCR of Childhood cancers with the guidance of International Agency for Research on Cancer (IARC) of WHO	Director - NCCP	X	X			
	Generate Report of PBCR of Childhood cancers with the PBCR Annual Report	Director - NCCP	X	X	X	X	X
6.1.4 Improve the section of childhood cancer incidence & mortality data with additional outputs in the National Cancer Registry Programme towards developing National Population based Childhood Cancer Registry	Develop SOPs on PBCR of Childhood cancers with the guidance of International Agency for Research on Cancer (IARC) of WHO	Director - NCCP	X	X			
	Generate relevant reports related to National Population based childhood cancer registry	Director - NCCP	X	X			
6.1.5 Commence hospital-based childhood & adolescent cancer registries in other Paediatric and adolescent Oncology units in the country	Develop an infrastructure and human resources plan for HBCR on childhood & adolescent cancer in other selected cancer treatment centers, in a phased manner.	Director of the hospital	X	X			
	Arrange training programmes for officer engage in cancer registration at these Oncology units	Director - NCCP	X	X	X		

<b>Strategic direction 6.2: Strengthen management information systems to monitor the progress and evaluate the outcomes of childhood and adolescent cancers</b>							
<b>Major Activities</b>	<b>Sub activities</b>	<b>Responsibility</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024</b>	<b>2025</b>
6.2.1 Establish a network connecting the central and provincial Paediatric cancer treatment centres with the details and updates of the current condition and management of the individual patients.	Link childhood cancer treatment centres with latest networking facility	Director of the hospital	X	X			
	Introduce Management Information System for monitoring childhood cancer care programme	Director of the hospital, NCCP	X	X			
6.2.2 Conduct the reviews of Childhood and adolescent cancer morbidity and mortality with the participation of Hospital Administrators, Consultant Paediatric Oncologists, Paediatricians, Paediatric surgeons, Radiologists, Histopathologists, Haematologists, Public Health & Primary Care Physicians, ..... etc	Develop SOPs for morbidity - mortality review of childhood cancers	Director-NCISL, Director -NCCP	X	X			
	Organize review meetings on childhood cancer statistics at each cancer treatment center with the relevant stakeholders.	Director-NCISL, Director -NCCP, Director MCH	X	X	X	X	X

## Strategic Objective 7 : Promote research related to childhood and adolescent cancers and utilization of its findings to inform optimal care

<b>Strategic direction 7.1: Promote of research related to childhood and adolescent cancers</b>							
<b>Major Activities</b>	<b>Sub activities</b>	<b>Responsibility</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024</b>	<b>2025</b>
7.1.1 Identify research priorities in relation to childhood and adolescent cancers in Sri Lankan setting (Epidemiological /Basic sciences / Clinical/ Health System)	Identify research priorities in relation to childhood and adolescent cancers	Director-NCCP, Director-Research, TAC on Childhood and Adolescent Cancers	x	X	x	x	x
	Disseminate research priorities through research seminars, web pages and social media			x	x	x	x
7.1.2 Increase funding opportunities for research on childhood and adolescent cancers	Communicate with government & non-government funding sources for increasing funding opportunities	Director-NCCP, Director-Research, TAC on Childhood and Adolescent Cancers, NGO sector	X	x	x	x	x
	Disseminate the information on availability of funds research			x	x	x	x
7.1.3 Promote undergraduate and post graduate research related to childhood and adolescent cancers	Disseminate research priorities to universities and postgraduate institutions	TAC on Childhood and Adolescent Cancers, Universities, DDG ET&R, Director NCCP		x	x	x	x
	Maintain a list of ongoing post graduate research projects related to cancer			x	x	x	x
	Encourage each institute to compile research evidence related to childhood and adolescent cancers			x	x	x	x
7.1.4 Establish a research facility with logistical support to conduct research related to childhood and adolescent cancers at the Paediatric Oncology unit, NCISL	Identify the requirements to commence a research facility to commence clinical research at the Paediatric Oncology unit, NCISL	Director-NCISL, TAC on Childhood and Adolescent Cancers, Director - NCCP		x			
	Communicate with Development Partners for logistical support			x	x	x	x

Major Activities	Sub activities	Responsibility	2021	2022	2023	2024	2025
	Facilitate to collaborate with research institute nationally and internationally for joint projects			x	x	x	x
7.1.5 Facilitate joining in international childhood and adolescent cancer clinical trials and research activities that will directly benefits Sri Lankan patients	Develop the concept paper describing the mechanism to facilitate joining clinical trials	DDG ET & R, Director NCISL, Professional Colleges, Clinical Trials units of research institutes, TAC on Childhood and Adolescent Cancers		x			
	Encourage interested research groups /institutes to communicate with clinical trials groups to explore possibilities			x	x	x	X
7.1.6 Establish a research hub focusing on childhood cancer, genetic etiological basis and palliative care	Explore the mechanism for establishing research hub focusing on childhood cancer and identify the focal point	DDG – ET & R, Director- NCISL Director - NCCP		x	x		
	Initiate developing research proposals with partnership of relevant focal points			x	x	x	x



<b>Strategic direction 7.2: Facilitate utilization of research evidence for clinical practice and service improvements</b>									
<b>Major Activities</b>	<b>Sub activities</b>	<b>Responsibility</b>	<b>2021</b>	<b>2022</b>	<b>2023</b>	<b>2024</b>	<b>2025</b>		
7.2.1 Facilitate conducting journal clubs, research seminars related to childhood and adolescent cancers	Identify coordinator and list funding & infrastructure requirements to commence the task	Director -NCISL, TAC on Childhood and Adolescent Cancers, Director - NCCP		x	x	x	X		
	Partnership with professional colleges, higher education institutes to commence the task			x	x	x	X		
7.2.2 Utilize locally conducted research to inform clinical, policy, administrative decision making	Compile locally conducted research related to childhood and adolescent cancers	DDG ET & R, Director NCCP, Director - Research, TAC on Childhood and Adolescent Cancers		x	x	x	X		
	Develop policy briefs based on research findings			x	x	x	X		
7.2.3 Publish and present the research findings in local & international forum	Organize cancer research seminars to create opportunity to present research findings	DDG ET & R, DDG - NCD, Director NCCP, Director - Research, TAC on Childhood and Adolescent Cancers		x	x	x	X		

## Results Framework

<b>Impact</b>
<ol style="list-style-type: none"><li>1. By 2030, achieve at least 60% survival for childhood cancer.</li><li>2. Reduce suffering of patients and their families due to childhood and adolescent cancers</li></ol>
<b>Desired Outcomes</b>
<ol style="list-style-type: none"><li>1) Strengthened national response for childhood and adolescent cancer care in Sri Lanka through leadership, advocacy and governance</li><li>2) Ensured timely and accurate diagnosis of childhood and adolescent cancers</li><li>3) Improved comprehensive cost-effective treatment for childhood and adolescent cancers</li><li>4) Ensured access to rehabilitation, long-term survivorship care and community reintegration of patients with childhood and adolescent cancers</li><li>5) Strengthened palliative care services to meet the needs of patients with childhood and adolescent cancers</li><li>6) Strengthened the management information system for childhood and adolescent cancer care</li><li>7) Evidence generated for childhood and adolescent cancer care</li></ol>

**1. Accelerate the national response for childhood and adolescent cancer care in Sri Lanka through an integrated national programme with leadership, advocacy and governance**

<b>Level</b>	<b>Narrative Summary</b>	<b>Indicators</b>	<b>Means of Verification</b>	<b>Key Assumptions</b>
<b>Outcome 1</b>	<b>Strengthened national response for childhood and adolescent cancer care in Sri Lanka through leadership, advocacy and governance</b>	Availability of National Strategic Plan on Childhood and Adolescent Cancer care in Sri Lanka	Document on National Strategic Plan	
<b>Output 1.1</b>	NSP for childhood and adolescent cancer care (2021 - 2025) is implemented and monitored	Availability of a Technical Advisory Committee (TAC) on Childhood and Adolescent Cancers to plan, coordinate, monitor and evaluate the national response  Number of TAC Meetings held per year out of the planned	Annual report of Progress of NSP  Minutes of the Technical Advisory Committee on Childhood and Adolescent cancers	
<b>Output 1.2</b>	Sustainable financing mechanisms identified to scale up optimal childhood and adolescent cancer care	Amount allocated for the implementation of National Strategic Plan on Childhood and Adolescent Cancer care per annum  Amount allocated from WHO Biennium for the identified activities of NSP	Annual report of Progress of NSP	
<b>Output 1.3</b>	Adequate health workforce is established for childhood and adolescent cancer care	Availability of human resource plan for Childhood and Adolescent Cancer care	Annual report of Progress of NSP	

<b>Output 1.4</b>	Developed master plans for infrastructure development and procurement of logistics	Availability of infrastructure development plan Availability of master plan for procurement of diagnostics and pharmaceuticals	Master plan reports on procurement of infrastructure	
<b>Output 1.5</b>	Established a network connecting the national, provincial cancer treatment centres and other relevant hospitals & professionals	Availability of a network connecting the national, provincial cancer treatment centres and other relevant hospitals & professionals	Annual report	

## 2. Ensure timely and accurate diagnosis of childhood and adolescent cancers in Sri Lanka

Level	Narrative Summary	Indicators	Means of Verification	Key Assumptions
<b>Outcome 2</b>	<b>Ensured timely and accurate diagnosis of Childhood and adolescent cancers</b>	Percentage of stage 1 & 2 selected childhood cancers among all diagnosed selected childhood cancers	Hospital Based Childhood Cancer Registry – NCI SL National Cancer Registry	Staging data are documented and entered to Cancer Registry
Output 2.1	Multi-disciplinary approach is incorporated into the process of diagnosis of childhood and adolescent cancers.	Number of multi-disciplinary meetings conducted for diagnosis of childhood and adolescent cancer	Report of Multidisciplinary team meetings.	

<b>Level</b>	<b>Narrative Summary</b>	<b>Indicators</b>	<b>Means of Verification</b>	<b>Key Assumptions</b>
Output 2.2	Strengthened the histopathology laboratory services for diagnosis of childhood and adolescent cancers	Availability of guidelines for procedure manuals in histopathology laboratory services for diagnosis of childhood and adolescent cancers.	Report of Guidelines	
Output 2.3	Strengthened haematology laboratory services for diagnosis of childhood and adolescent cancers	Availability of guidelines on haematological diagnosis and follow up for childhood and adolescent cancers	Availability of Guidelines	
Output 2.4	Strengthened chemical pathology laboratory services for diagnosis of childhood and adolescent cancers	Availability of guidelines on chemical pathology for diagnosis and follow up for childhood and adolescent cancers	Availability of Guidelines	
Output 2.5	Strengthened molecular & genetic testing facilities for diagnosis of childhood and adolescent cancers	Commencement of molecular and genetic testing facility at NCI SL	Report of molecular and genetic testing facility	
Output 2.6	Strengthened radiological services for diagnosis of childhood and adolescent cancers	Availability of PACS system for sharing patient information within and between hospitals	Report of functioning PACS systems at NCISL & LRH	

### 3. Improve comprehensive cost-effective treatment options for childhood and adolescent cancers including chemotherapy, radiotherapy, surgery and other novel therapeutic modalities

Level	Narrative Summary	Indicators	Means of Verification	Key Assumptions
<b>Outcome 3</b>	<b>Improved comprehensive cost-effective treatment for childhood and adolescent cancers</b>	Availability of comprehensive treatment facilities for Childhood cancers at National Cancer Institute  Availability of comprehensive surgical care facilities for management of childhood cancers at Lady Ridgeway Hospital for Children	Report of NCI SL  Report of LRH	Availability of technical experts
Output 3.1	National Cancer Institute OF Sri Lanka functioned as the centre of excellence for childhood and adolescent cancer care in Sri Lanka	Availability of state of art childhood and adolescent cancer care unit at National Cancer Institute	Report of NCI SL	Availability of Funds  Availability of International partnership for commencing Razavi Project II for Childhood cancer care wing
Output 3.2	Strengthened childhood and adolescent cancer care at the identified cancer treatment centres in the country in equitable manner	No. of aediatric cancer centres functioning out of the number planned  % of treatment centres providing treatment for acute lymphocytic leukaemia (ALL) for childhood and adolescent cancer patients	Report of Cancer Treatment centres	
Output 3.3	Strengthened comprehensive care for childhood and adolescent cancer patients at the	Availability of guidelines/protocols /SOPs for management of childhood and adolescent cancer care	Availability of guidelines/protocols /SOPs	

<b>Level</b>	<b>Narrative Summary</b>	<b>Indicators</b>	<b>Means of Verification</b>	<b>Key Assumptions</b>
	identified cancer treatment centres			
Output 3.4	Upgraded the intensive care units and emergency treatment units for critically ill childhood and adolescent cancer patients	No. of ICU beds available for Childhood cancer patients at NCISL  Availability of guidelines for management of Paediatric cancer emergencies	Report of NCISL	Availability of funds for expansion of Paediatric ICU at NCISL
Output 3.5	Ensured supply of quality assured medicines in appropriate strengths and dosage forms for childhood and adolescent cancer care	Availability of National Essential Medicine list for Paediatric oncology  Availability of National Quality Assurance laboratory	Report of MSD	
Output 3.6	Improved surgical care for childhood and adolescent cancer care	No. of childhood cancer patients received timely surgical care out of those childhood cancer patients who required surgery as a treatment option	Report of LRH  Hospital Based Childhood Cancer Registry – NCI SL	Functioning Hospital Based Cancer Registry at NCI SL
Output 3.7	Strengthened radiotherapy facilities for childhood and adolescent cancer care	No. of childhood cancer patients received radiotherapy on time out of those childhood cancer patients who required radiotherapy	NCI SL Report	Requirements for radiotherapy for childhood cancer patients are fulfilled.
Output 3.8	Strengthened microbiological services for childhood and adolescent cancer care	Availability of guidelines and protocols for early diagnosis of sepsis of childhood cancer patients  Availability of Standard Operational Procedures to minimize anti-microbial resistance	Availability of guidelines and protocols and SOPs	

Level	Narrative Summary	Indicators	Means of Verification	Key Assumptions
Output 3.9	Commenced advanced treatment options for childhood and adolescent cancer care	Number of special training programmes conducted to health care staff to initiate stem cell transplantation for childhood cancers	NCISL Report	
Output 3.10	Improved services on pain free procedures for the treatment of childhood and adolescent cancer care	Number of Paediatric oncology units which established procedure room.	NCISL Report	
Output 3.11	Improved the services on psycho- social and spiritual needs of children and adolescents with cancer	Number of newly established parent support groups/ bravery groups	NCISL Report	

#### 4. Ensure access to rehabilitation, long-term survivorship care and community reintegration of patients with childhood and adolescent cancers

Level	Narrative Summary	Indicators	Means of Verification	Key Assumptions
<b>Outcome 4</b>	<b>Ensured access to rehabilitation, long-term survivorship care and community reintegration of patients with childhood and adolescent cancers</b>	Availability of rehabilitation and long term survivorship care for childhood and adolescent cancer patients	NCI SL report Periodic survey	Availability of funds and human resources



<b>Level</b>	<b>Narrative Summary</b>	<b>Indicators</b>	<b>Means of Verification</b>	<b>Key Assumptions</b>
Output 4.1	Improved counselling services for the patients with childhood and adolescent cancers and their families	Number of training programmes on basics of communication and counselling for the medical, nursing staff and other categories of staff working at the Paediatric cancer units	NCI SL report	Availability of funds and human resources
Output 4.2	Established rehabilitation and survivorship services for cancer care	Percentage of cancer Treatment centres with childhood and adolescent rehabilitation and survivorship services	District Review formats Special surveys	
Output 4.3	Strengthened the services on long term survivorship care for childhood and adolescent cancers	Number of survivorship clinics established at Paediatric cancer units	District Review formats Special surveys	
Output 4.4	Family and community empowered for childhood and adolescent cancer care	Percentage of hospitals with training programmes for family members of children and adolescents with cancers.	District Review formats Special surveys	

## 5.Ensure access to palliative care services to meet the needs of patients with childhood and adolescent cancers and their families

Level	Narrative Summary	Indicators	Means of Verification	Key Assumptions
<b>Outcome 5</b>	<b>Strengthened palliative care services to meet the needs of patients with childhood and adolescent cancers</b>	Percentage of childhood & adolescent cancer patients received specialized palliative care service from the established palliative care service	Annual Report of Paediatric palliative care service at NCI SL	Availability of funds and human resources
Output 5.1	Strengthened care on palliative care services on childhood and adolescent cancers	Percentage of cancer treatment hospitals with Paediatric palliative care services	Special survey reports  Review minutes	
Output 5.2	Empowered health care team and other stakeholders	Number of basic, post basic, Diploma and MD programmes which incorporated with Paediatric palliative care inputs	Basic, post basic, Diploma and MD programme curricula	

**6.Strengthen the management information system including cancer registries and comprehensive medical records to monitor the progress and evaluate the outcomes of childhood and adolescent cancers.**

Level	Narrative Summary	Indicators	Means of Verification	Key Assumptions
<b>Outcome 6</b>	<b>Strengthened the management information system for childhood and adolescent cancer care</b>	Availability of Hospital Based Childhood Cancer Registry at NCI SL  Availability of updated National Cancer Registry with childhood cancer incidence data	Hospital Based Childhood Cancer Registry report  National Cancer Registry report	Availability of funds, human resources, hardware and software maintenance agreements
Output 6.1	Strengthened cancer registries to monitor the progress and evaluate the outcomes of childhood and adolescent cancers.	Availability of timely publication of Hospital Based Cancer Registry report with outcome /survival data  Availability of updated National Cancer Registry report with childhood cancer incidence data	Hospital Based Childhood Cancer Registry report  National Cancer Registry report	
Output 6.2	Strengthened management information systems to monitor the progress and evaluate the outcomes of childhood and adolescent cancers	Availability of patient management information system for childhood cancer patient management.  Number of reviews of childhood and adolescent cancer morbidity and mortality conducted	Electronic patient management system at NCISL  Report of NCISL	

**7.Promote research related to childhood and adolescent cancers and utilization of its findings to inform optimal care and wellbeing of families**

<b>Level</b>	<b>Narrative Summary</b>	<b>Indicators</b>	<b>Means of Verification</b>	<b>Key Assumptions</b>
<b>Outcome</b>	<b>Evidence generated for childhood and adolescent cancer care</b>	Availability of report of change of practices or policies based on research evidence	Report of NCCP	
Output 7.1	Priority researches related to childhood and adolescent cancer care conducted	Proportion of priority research conducted annually. No. of research publications per year	Report of NCCP	
Output 7.2	Research evidence are translated into practice for childhood and adolescent cancer care	Availability of report on research findings utilized for routine practice	Report of NCCP	

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