



# CureAll Framework: WHO Global Initiative for Childhood Cancer



World Health  
Organization

Increasing access, advancing quality, saving lives



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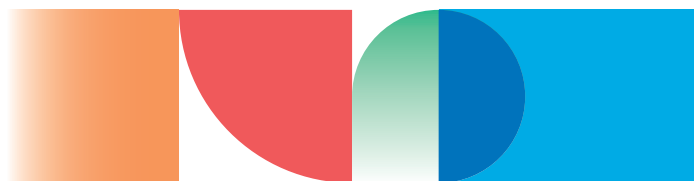
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# CONTENTS

<b>Foreword.</b>	v
<b>Acknowledgements</b>	vii
<b>Abbreviations and acronyms</b>	viii
<b>Executive summary</b>	ix
<b>Purpose, scope and audience</b>	xi
 <b>1. Overview.</b>	 2
<b>1.1 Introducing childhood cancer</b>	4
1.1.1 What is childhood cancer?	6
1.1.2 Childhood cancer as a distinct cancer group	6
<b>1.2 Understanding the disease burden.</b>	7
1.2.1 Global incidence and mortality	8
1.2.2 Childhood cancer survival	12
1.2.3 Access to childhood cancer services	14
1.2.4 Social and economic impact of childhood cancer	14
<b>1.3 Understanding the cause of inequity.</b>	16
<b>1.4 Childhood cancer in the public health agenda</b>	17
1.4.1 Global commitments to childhood cancer	18
1.4.2 Global Initiative for Childhood Cancer	22
<b>1.5 Investment case.</b>	22
1.5.1 Evidence of cost-effective childhood cancer intervention	24
1.5.2 Generating an investment case in childhood cancer	24
 <b>2. Strategic approach of CureAll.</b>	 26
<b>2.1 Objectives of the WHO Global Initiative for Childhood Cancer</b>	28
<b>2.2 CureAll framework: pillars and enablers</b>	31
<b>2.3 Tracer cancers</b>	32
<b>2.4 Childhood cancer care pathway</b>	33
2.4.1 Family-centred, multidisciplinary care	35
2.4.2 Palliative care	37
2.4.3 Survivorship care.	39
 <b>3. CureAll: priority interventions.</b>	 42
<b>3.1 Pillar 1: Centres of excellence and Care networks to increase access to quality health services</b>	44
Rationale.	44
What to do.	47
Sample metrics	52
Case study	53

# CONTENTS

<b>3.2 Pillar 2: Universal health coverage (UHC) and integration of childhood cancer . . . .</b>	<b>54</b>
Rationale. . . . .	54
What to do. . . . .	56
Sample metrics . . . . .	59
Case study . . . . .	60
<b>3.3 Pillar 3: Regimens optimized for delivery of quality diagnostic and treatment services</b>	<b>61</b>
Rationale. . . . .	61
What to do. . . . .	63
Sample metrics . . . . .	66
Case study . . . . .	66
<b>3.4 Pillar 4: Evaluation and monitoring with information systems to improve outcomes</b>	<b>67</b>
Rationale. . . . .	67
What to do. . . . .	72
Sample metrics . . . . .	75
Case study . . . . .	75
<b>3.5 Enablers . . . . .</b>	<b>76</b>
3.5.1 Enabler 1: Advocacy. . . . .	76
3.5.2 Enabler 2: Leveraged financing . . . . .	79
3.5.3 Enabler 3: Linked governance . . . . .	81
Sample metrics . . . . .	84
<b>4. Approach to implementation . . . . .</b>	<b>86</b>
<b>4.1 Accelerating impact in countries and regions. . . . .</b>	<b>88</b>
<b>4.2 Implementation approach. . . . .</b>	<b>91</b>
Assess. . . . .	91
Plan, cost and finance: prioritization and policy dialogues . . . . .	92
Implement . . . . .	92
Monitor and modify. . . . .	93
<b>4.3 Theories of change in childhood cancer . . . . .</b>	<b>93</b>
<b>4.4 Results chain for CureAll technical package . . . . .</b>	<b>94</b>
<b>4.5 Toolkit for implementing CureAll . . . . .</b>	<b>95</b>
<b>5. Conclusion. . . . .</b>	<b>98</b>
<b>References. . . . .</b>	<b>100</b>
<b>Annex: GICC Working group members (Phase I) . . . . .</b>	<b>106</b>




**Tedros Adhanom Ghebreyesus**  
Director-General  
World Health Organization



## FOREWORD

### **Increasing access, advancing quality, saving lives**

Care for cancer, like so many other diseases, reflects the inequalities and inequities in our societies. The impact on children is devastating.

Each year, an estimated 400 000 children are diagnosed with cancer around the world. The vast majority of these children live in low- and middle-income countries, where treatment is often unavailable, unaffordable or of poor quality.

The survival rate for these children is estimated to be between 15% and 45%. This compares to a survival rate of more than 80% in high-income countries.

Where a child lives should not determine whether he or she survives.

To address this profound inequity, WHO and St. Jude Children's Research Hospital launched the WHO Global Initiative for Childhood Cancer in 2018.

The Initiative brings together partners and stakeholders across sectors towards a shared goal of improving health and well-being for children with cancer using the **CureAll** framework as a shared operational approach. By 2030, the Initiative aims to achieve at least 60% survival for childhood cancer globally and reduce suffering for all.

This approach aims to take into account the special needs of children, including their development, socioeconomic issues, and family participation in care. It requires a specialized workforce, complex multidisciplinary care and advocacy. In particular, attention must be given to children's nutrition, psychosocial well-being, neurocognitive and reproductive health, growth and long-term outcomes.

We are already seeing progress. Fifteen governments have committed to strengthen childhood cancer programmes, using the **CureAll** framework described in this document. More than 110 partner organizations have come to the table to support them. Three WHO regional networks have been developed, allowing for rapid expansion of impact to more than 50 countries. This has translated into real improvement in the lives of children with cancer.

Achieving the Sustainable Development Goals and universal health coverage based on primary health care means that governments, health systems, communities, and all other stakeholders must work together to address the underlying inequalities that mean some children have a better chance than others. Every child with cancer, and every child, deserves high-quality care. I believe this is a goal within our reach – **together**.





**Dr James R Downing**

St. Jude Children's Research Hospital  
President and Chief Executive Officer




The St. Jude Children's Research Hospital mission is to advance cures and means of prevention for paediatric catastrophic diseases through research and treatment. Our work has helped raise cure rates for paediatric cancer to 80% in the United States. Unfortunately, children worldwide do not share this hopeful outlook. In fact, survival rates fall below 30% internationally.

Through St. Jude Global, the Global Alliance, serving as a WHO Collaborating Centre for Childhood Cancer and partnering with WHO to launch the Global Initiative for Childhood Cancer, we seek to improve the statistics.

Our goal is to raise paediatric cancer survival rates to 60% worldwide by 2030 and ensure a day when children everywhere have access to quality care.

The dream is bold, but within reach. At St. Jude, we have seen what success is possible when people come together with a shared purpose. Imagine the future we can build by uniting the world to tackle paediatric cancer.



As children, we are not only the future, but also the present of this world. Our future depends on the adults of today. 



**Gabriel "Gabo" Alessandro Mayorga**

Survivor of acute lymphoblastic leukaemia





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# ABBREVIATIONS AND ACRONYMS

<b>AYA</b>	adolescents and young adults
<b>DALYs</b>	disability-adjusted life years
<b>EDL</b>	Essential Diagnostics List (WHO Model List of Essential in vitro Diagnostics)
<b>EML</b>	Essential Medicines List (WHO Model List of Essential Medicines)
<b>HBCR</b>	hospital-based cancer registry
<b>HIC</b>	high-income country
<b>HIS</b>	health information system
<b>LIC</b>	low-income country
<b>LMIC</b>	low- and middle-income country
<b>NCD</b>	noncommunicable disease
<b>PBCR</b>	population-based cancer registry
<b>QI</b>	quality improvement
<b>SDG</b>	Sustainable Development Goal
<b>UHC</b>	universal health coverage
<b>US</b>	United States of America
<b>WHO</b>	World Health Organization



# EXECUTIVE SUMMARY

Every day, more than 1000 children (aged 0–19 years) are diagnosed with cancer. For a child living in a high-income country able to access optimal care, the likelihood of surviving exceeds 80%. Unfortunately, survival is only 15–45% for the vast majority of children with cancer who live in low- and middle-income countries (LMIC). There is a complex interplay of factors contributing to this profound global inequality, rooted in weak health systems unable to meet the needs of children and their families and weak political prioritization of childhood cancer.

Yet, progress is achievable, and improving outcomes in childhood cancer in the short term has been reliably demonstrated in multiple settings and across different health systems. Improving childhood cancer care offers an important opportunity, not only to save lives and reduce suffering, but also to catalyse progress towards a more inclusive cancer control programme and to demonstrate success in the broader child health and noncommunicable disease (NCD) agenda.

The inclusion of childhood cancer as a public health priority is feasible, effective and sustainable. Investing in childhood cancer programmes has capacity to save hundreds of thousands of lives per year at a low per capita cost (\$US 0.03–0.15 for LMIC). Greater investments in childhood cancer programmes, research and innovation will promote equity, accelerate progress towards optimal outcomes and drive social development and economic growth for all.

It is in this context that the World Health Organization (WHO), alongside St. Jude Children's Research Hospital and working with other global partners, launched the WHO Global Initiative for Childhood Cancer at the September 2018 United Nations General Assembly Third High-level Meeting on the prevention and control of NCDs. The target of this Initiative is to achieve at least 60% survival for children with cancer globally while ensuring that suffering is reduced for every child. The Initiative brings together stakeholders across sectors towards a shared goal using the **CureAll** framework as the coordinated operational approach.

The **CureAll** framework and accompanying technical package are designed to support countries implement this Initiative and strengthen childhood cancer programmes. There are four pillars and three enablers in the **CureAll** framework with accompanying priority actions and metrics. The framework focuses on the broader needs of children with cancer including their growth, learning, development, nutrition, psychosocial well-being, reproductive health and long-term outcomes. This framework uses an integrated child-centred care approach with particular attention to the socioeconomic impact of childhood cancer diagnosis on families.

Section 1 provides a background to childhood cancer, including disease burden, recent progress in childhood cancer care, the causes of inequities of childhood cancer morbidity and mortality and an economic justification for the need to address childhood cancer care.

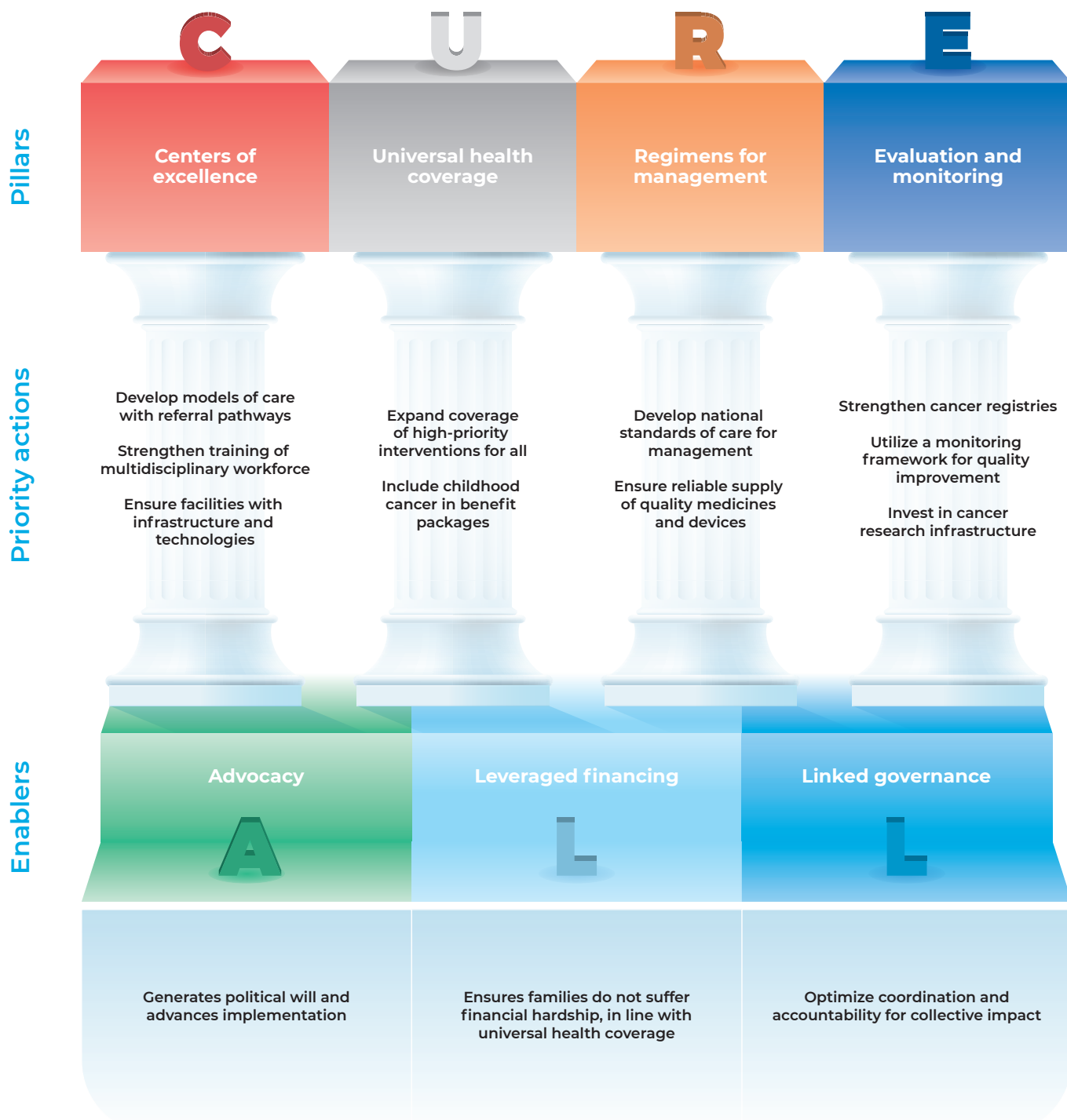
Section 2 demonstrates the **CureAll** approach of the WHO Global Initiative for Childhood Cancer; and outlines the specificities of the childhood cancer pathway, including the need for multidisciplinary and family-centred care.

Section 3 centres on the pillars and enablers (Figure 1) providing a rationale and context information for each pillar and enabler. The framework itemizes evidence-based strategies and priority actions to increase the capacity of countries to provide quality childhood cancer services.

Section 4 is an implementation guide. It provides details on the four steps needed to implement the **CureAll** approach: Assess, Plan, Implement and Monitor.

The justifications for action are strong, evidence-based guidance on priority activities are robust; and the stakeholder's commitments to implementation are unwavering. Children deserve to be cared for regardless of where they live. If we act together, today, the lives of one million children can be saved over the next decade.

Figure 1. CureAll Framework





## PURPOSE, SCOPE AND AUDIENCE

The technical package for the WHO Global Initiative for Childhood Cancer (referred to as the Initiative) is a suite of tools and products to support governments to implement the Initiative using **CureAll** as an operational approach. This document, the **CureAll** framework: WHO Global Initiative for Childhood Cancer follows the Global Initiative for Childhood Cancer: an overview (7) and acts as the reference technical product for the broader Initiative (Figure 2).

### PURPOSE

The purpose of this framework document is to present the operational details for implementing the **CureAll** approach, focusing on the rationale and priority interventions. It aims to increase the capacity of countries to provide quality services for children with cancer, and to support the prioritization of childhood cancer at the global and national levels.

This framework document is a “how-to” guide for policy-makers and programme managers to effectively implement the **CureAll** pillars and enablers. It provides justification for action, posits priority interventions and proposes a monitoring framework. Key components needed to establish, scale up and sustain a well-functioning national childhood cancer programme are explained.

### SCOPE

The scope of this framework document is centrally defined by the programmes, services and policies that support children with cancer in the context of the health system. For the Initiative, children are defined as those aged 19 years or younger. Childhood cancer care requires cross-cutting strategies, such as workforce training, that often have overlap with broader child health and/or cancer control programmes. These synergies are highlighted and considered in scope for the Initiative and for an integrated response in childhood cancer control.

### AUDIENCE

The primary audience for this framework document are policy-makers, cancer control programme managers and hospital managers at the country level. Additional key stakeholders may also find the information in this guide beneficial, including clinicians, parent groups, civil society, academia and interested parties in the private sector.

**Figure 2.** Technical Package for WHO Global Initiative for Childhood Cancer





“Better Survival”  
means hope, and a  
future with better  
and more effective  
treatment”

— Ava

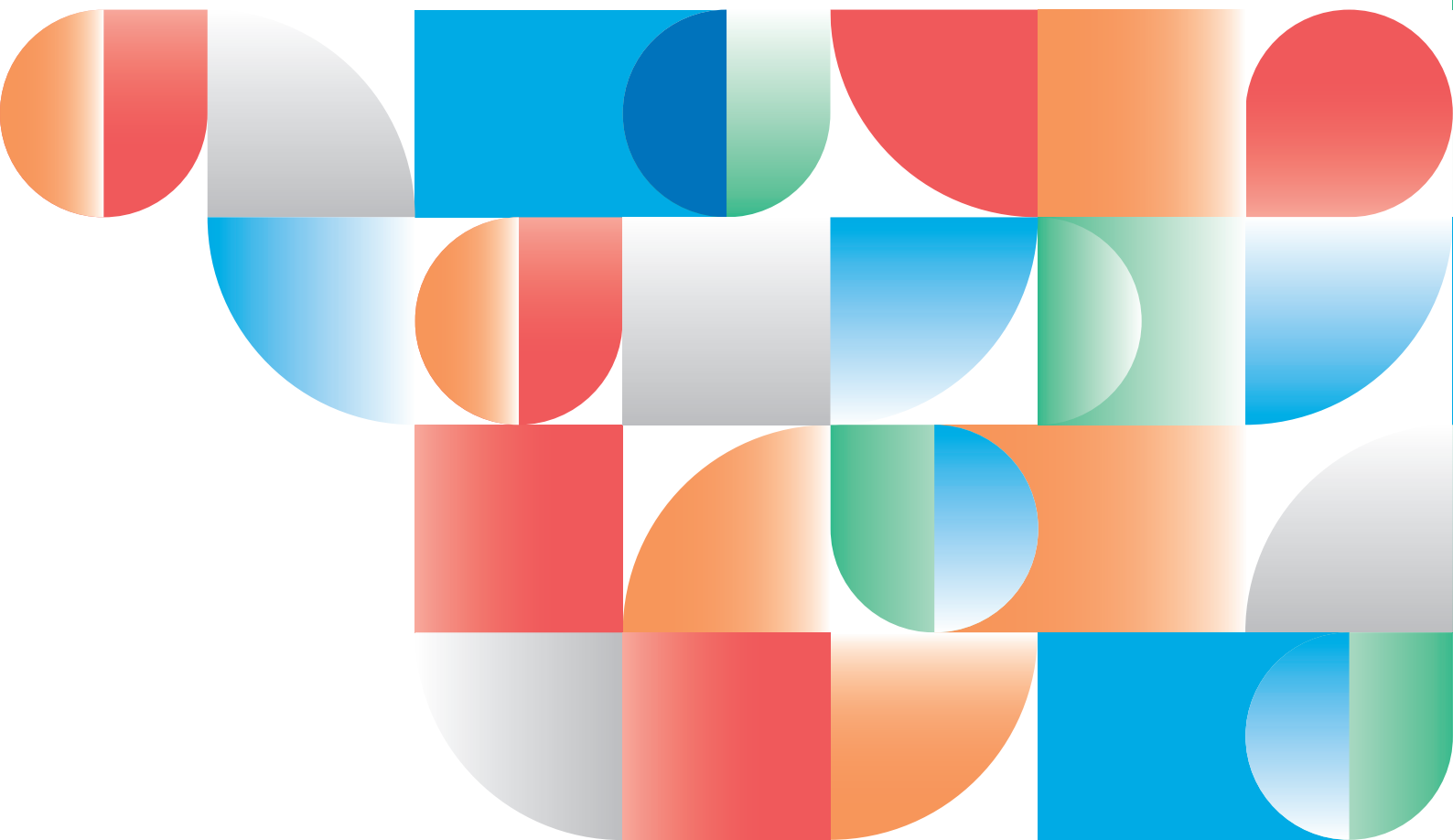
Survivor of acute lymphoblastic leukaemia

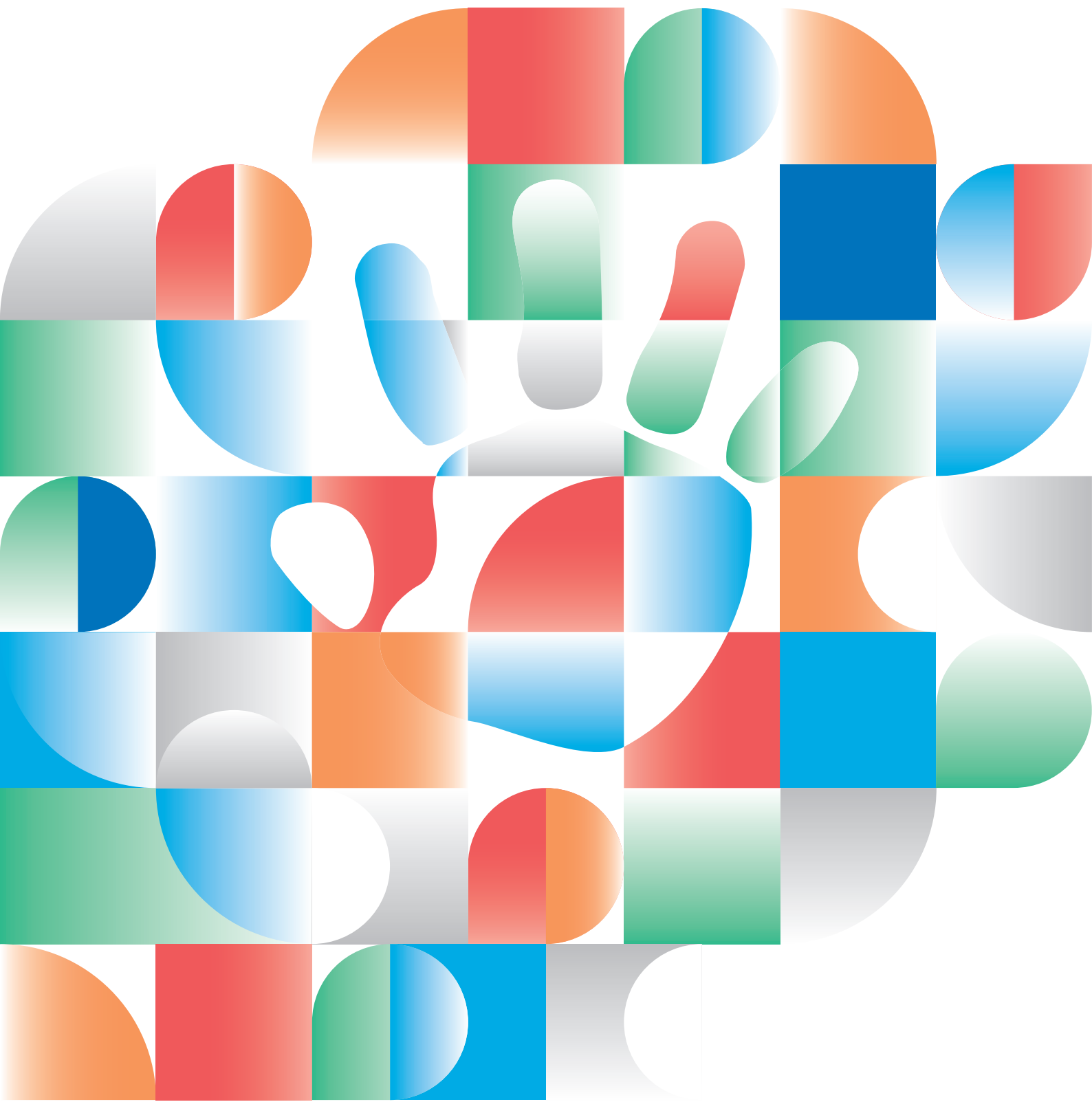




**Section 1.**

# Overview







# 1.1 INTRODUCING CHILDHOOD CANCER

Childhood cancer presents a significant and relevant public health challenge: the burden is overwhelming for the affected families; inequalities are profound; and it is an important tracer for progress in the broader health agenda.

An accurate understanding of and commitment to controlling childhood cancer can be transformative, resulting in improved population health, social cohesion (2) and broader economic prosperity (Section 1.5). However, misperceptions of childhood cancer are too common (Box 1).

## Box 1. Dispelling myths and misconceptions



**Myth:**  
**Children do not develop cancer**

### Fact:

Cancer can develop at any age, including in newborns. While the likelihood of cancer generally increases with age, approximately 400 000 children globally (aged 0–19 years) develop cancer each year. That is equivalent to about one in 500 children in their lifetime (3).



**Myth:**  
**Childhood cancers are preventable**

### Fact:

Unlike adult cancers, almost all childhood cancers arise during growth and development and cannot be prevented. Rather than prevention programmes, effective childhood cancer control must focus on avoiding missed/delayed diagnosis, ensuring access to high-quality multidisciplinary care, reducing and managing disease- and treatment-related complications, ensuring treatment completion and sustained follow-up of long-term survivors.



**Myth:**  
**Most children with cancer die of their disease**

### Fact:

More than 8 of 10 children are cured when they receive the best available treatment services and care (Section 1.2.2). Research and innovation remain important priorities for further improvements in childhood cancer care.



**Myth:**  
**Childhood cancer is one disease, treated with a standardized approach**

### Fact:

There are many different cancers of children and young people that develop at different ages, in many parts of the body and with different patterns of spread. The diagnosis and treatment must be adapted to the individual and follow evidence-based standards of care.



**Myth:**  
**Childhood cancer chemotherapy is expensive**

### Fact:

Most children can be cured using inexpensive generic medicines and affordable multimodality therapy (Section 1.5).



**Myth:**  
**Even if children survive cancer, they are left with permanent and severe disabilities**

### Fact:

While treatment can cause health care needs in some survivors, many children cured of cancer go on to lead long, happy, healthy and productive lives.



Rodrigo Gaitán, AYUVI/Unidad  
Nacional de oncología pediátrica, Guatemala

The key message of childhood cancer control is that **small, strategic investments can save lives and improve the overall health system.**

Since childhood cancer exists at the intersection of multiple public health areas, progress in major disease-specific programmes and clinical services, including child health, community health and noncommunicable diseases (NCDs) can strengthen the broader health system. With appropriate implementation founded on evidence-based standards, community action and cooperation within networks, immediate progress in childhood cancer care can be achieved (4).

### 1.1.1 WHAT IS CHILDHOOD CANCER?

Childhood cancer is a diverse and heterogeneous group of rare cancers (5) that are unified by the age of the cohort. For the purposes of the Initiative, childhood cancer is defined as the group of cancer that arises between birth and 19 years of age. It should be noted, however, that countries use different and acceptable thresholds for childhood cancer.

The cells from which childhood cancers originate are generally not the same as adult cancers. Childhood cancers derive from embryonal tissues that have acquired mutations resulting in an uncontrolled division of abnormal cells. If left untreated, these abnormal cells quickly spread throughout the body (metastasize), causing further harm and, ultimately, death. Timely diagnosis followed by appropriate therapies removes or kills the cancerous cells, resulting in cure.

In general, the most common childhood cancers are leukaemia (bone marrow and the lymphatic system), central nervous system tumours, neuroblastoma (multiple sites, commonly adrenal glands), lymphoma (immune cells), and kidney tumours and bone tumours, although this may vary slightly by geography (Section 1.2).

Potential causes of childhood cancer are not well understood. At the current state of knowledge, very few childhood cancers are preventable. In contrast, cancers in adults are linked to certain behaviours (e.g. smoking, alcohol, diet) and environmental exposures, which allow implementation of preventive measures (6). The origin of many childhood cancers is believed to occur during corrupted growth of organs and tissues during development before birth. A very small percentage of childhood cancers have a known aetiology that may include: (i) intrauterine exposure (radiation, toxins); (ii) infection (Epstein-Barr virus, cytomegalovirus); or (iii) genetic predisposition syndromes (retinoblastoma, Down syndrome, Li-Fraumeni, neurofibromatosis, others) (7,8).

Thus, the approach to childhood cancer control is similar to other cancers in one way: it requires strong public health programmes, with timely and robust referral processes linked to high-quality clinical services. Treatment services must be multidisciplinary (also known as inter-professional) and include multimodality therapies across the cancer continuum (9). High rates of survival in well-resourced settings are based on research-driven childhood cancer protocols (10).

### 1.1.2 CHILDHOOD CANCER AS A DISTINCT CANCER GROUP

Fundamentally, childhood cancers are similar to all cancers: they are marked by the rapid extension of abnormal cells, which have accumulated genetic and epigenetic abnormalities, and acquired the capacity for uncontrolled growth, proliferation and spread through the body (metastasis) that, left untreated, lead to untimely death.

However, childhood cancers are different from adult cancers in two general ways. First, unlike adult cancers, which generally occur in mature tissues, childhood cancers arise in developing organs and tissues, they generally grow rapidly over a few weeks to months, and their patterns of spread through the body are different. This fast growth means they may have few or subtle symptoms and may make the child become critically ill quickly, often mimicking other

childhood illness such as infection. Second, because childhood cancers arise in developing and growing tissues, they have distinct tumour biology, microscopic appearance and clinical behaviour. The tumour biology gives rise to unique and acquired genetic changes within the cancer that can influence the cancer's growth and its prognosis.

Arising where they do and because of their rapid growth and spread, paradoxically makes many childhood cancers more sensitive and responsive to cancer chemotherapy than in most adult cancers (11,12). Accordingly, the treatment of childhood cancer is more reliant on chemotherapy (in addition to surgery and radiotherapy) than adult cancers. Chemotherapy in childhood cancer treatment is also able to treat the microscopic spread of these cancers.

Moreover, most childhood cancers are treated with greater intensity and with higher relative chemotherapy doses than adults; as their tumours respond quicker, children generally tolerate chemotherapy better than adults and have fewer co-morbidities (13). However, the rapid growth of childhood cancers and the treatment intensity means that for the best outcome, therapy needs to be given consistently and without undue interruption or delay.

Like in children, the cancers in adolescents and young adults (AYA) also have a distinct biology and clinical behaviour that differ from both adults and younger children. The distribution of cancer types seen in adolescents aged 15–19 years old is unique and includes lymphomas (Hodgkin but also non-Hodgkin), leukaemia (acute lymphoblastic leukaemia primarily and acute myeloid leukaemia), germ cell tumours of the ovary and testis, muscle and bone tumours, brain tumours and thyroid cancer. In the older AYA population (30 years and older), melanoma, breast and colorectal cancers become the most common cancers seen.

The epidemiology of AYA cancer is also changing, with an increasing incidence AYA cancers, in particular of obesity-related cancers (14).

The special needs of children are particularly important during and after cancer treatment; and served by multidisciplinary care. For example, the consistent and continuous observation of the physical, neurocognitive and psychosocial growth of the child is crucial. Multidisciplinary services should thereby include routine service provision in nutritional and psychosocial support, fertility preservation, physical therapy and others, centred on the needs of the child and family.

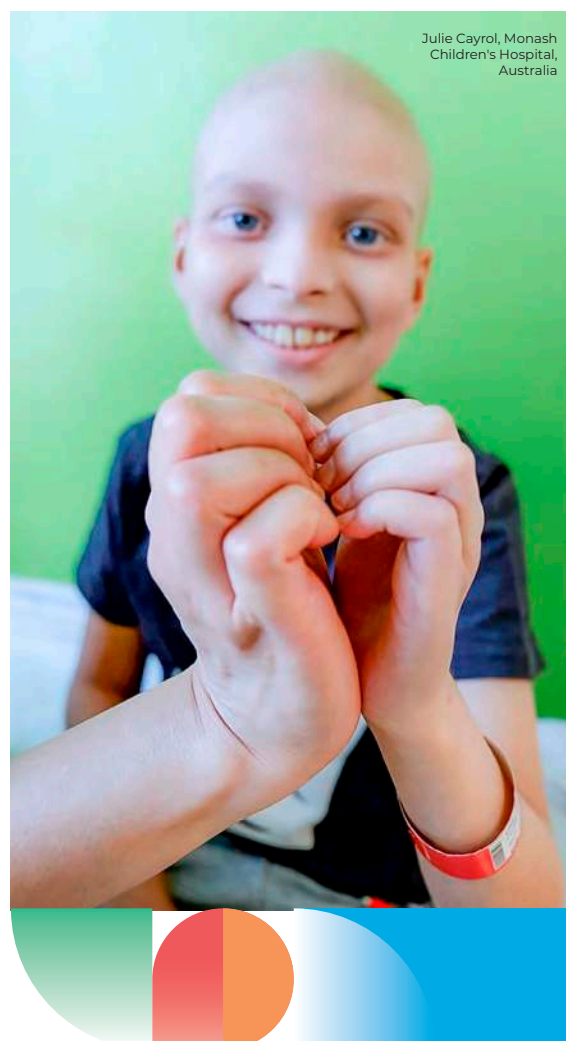
As all these children and adolescents are cured, they need ongoing support and long-term follow-up to address the effects of the therapies on their health as adults, such as fertility, cardiovascular, endocrine and pulmonary functions as well as educational attainment and financial stability.



## 1.2 UNDERSTANDING THE DISEASE BURDEN

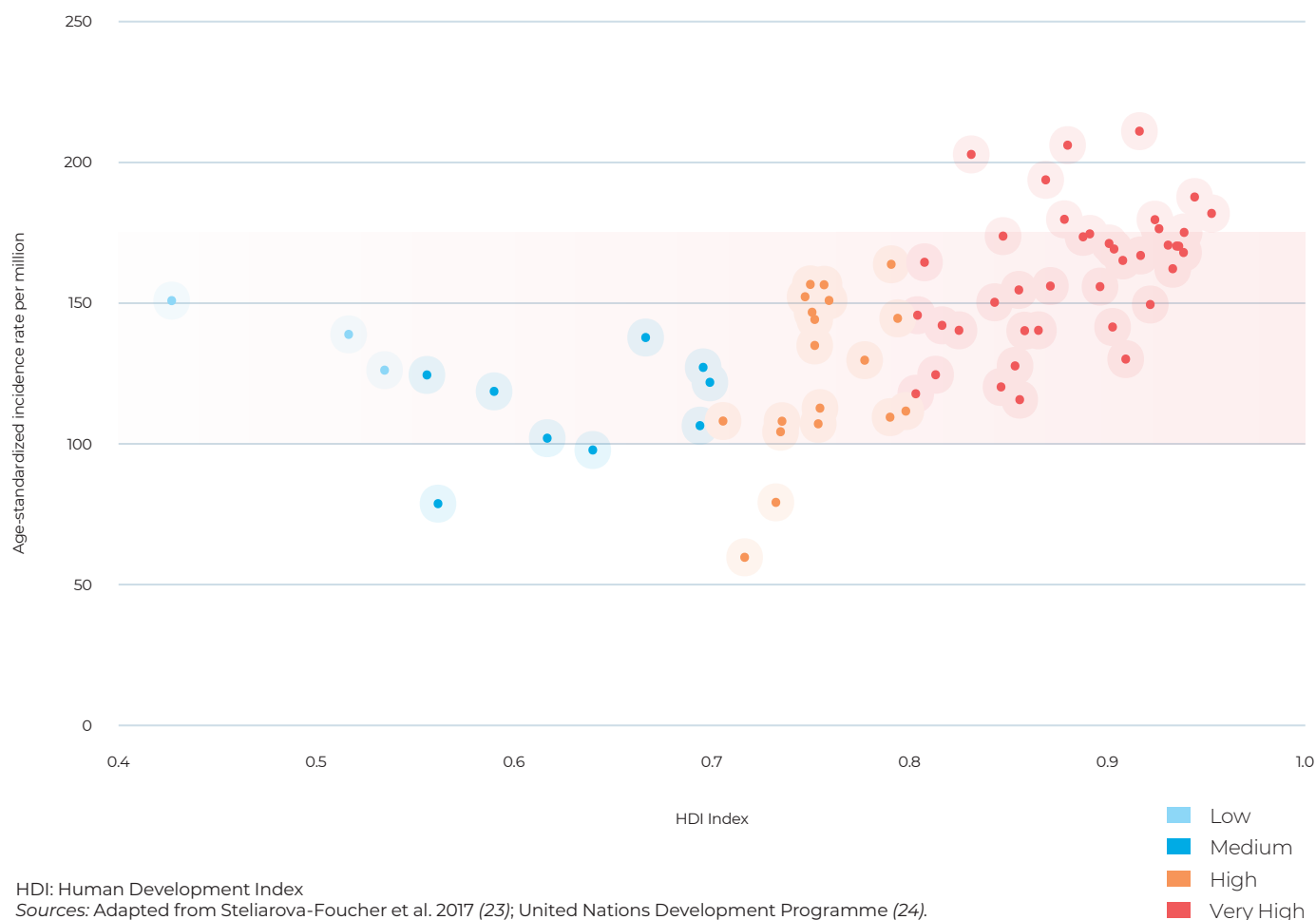
The global burden of cancer is significant and increasing. It is estimated that 19 million new cases and 10 million deaths have occurred in 2020 in all ages (15). More than one in six deaths in 2019 globally is due to cancer, and cancer is responsible for approximately 25% (5.1 million) of the premature deaths that occur before the age of 70 (16). The global burden of cancer continues to rise due to an increasing life expectancy and epidemiological and demographic transitions of settings previously burdened by NCDs (6).

Childhood cancers are a substantial contributor to the global disease burden, affecting children and their families all around the world. Each year, an estimated 400 000 children aged 0–19 years develop cancer globally (17). Increasingly, childhood cancer represents a substantive contributor to disability-adjusted life years (DALYs), surpassing select other childhood diseases and adult cancers (18,19). DALYs are the sum of years of potential life lost due to avoidable mortality and the years of productive life lost due to disability.





**Figure 3.** Age-standardized incidence rate of childhood cancer (0–19 years old) in selected countries, by Human Development Index



## 1.2.1 GLOBAL INCIDENCE AND MORTALITY

### CHILDHOOD CANCER **INCIDENCE**

Of nearly 400 000 children aged 0–19 years estimated to develop cancer every year, approximately 90% occur in low- and middle-income countries (LMIC), where nearly 95% of children in this age group live and health systems are often weaker and consequentially cancers often go undiagnosed and untreated (20,21). Giving consideration to the population distribution and data availability, existing data indicate that childhood cancer incidence remains similar irrespective of developmental status (Figure 3).

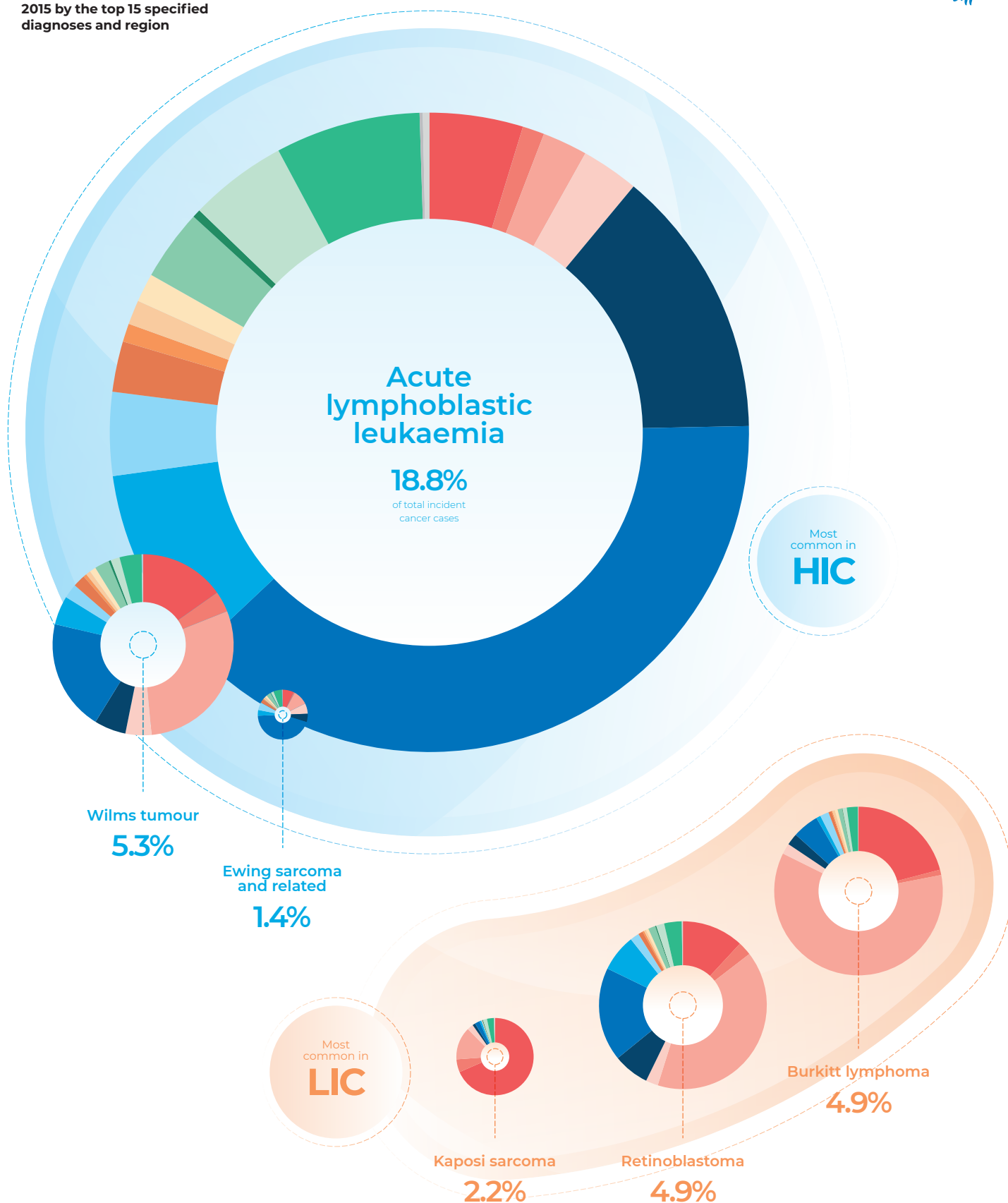
Globally, acute lymphoblastic leukaemia is the most common childhood cancer and is estimated to account for 19% of total childhood cancer incidence, followed by non-Hodgkin lymphoma (5%), nephroblastoma (5%), Burkitt lymphoma (5%) and

retinoblastoma (5%) (17). Over a third (34.1%) of all childhood cancer DALYs are estimated to be attributable to leukaemia (34%), followed by just under one fifth (19%) attributable to central nervous system tumours in 2019 (22).

The most common cancer differs by region. For example, the incidence of acute lymphoblastic leukaemia is significantly lower in sub-Saharan Africa than in other regions. The overall higher cancer burden in many African countries is attributable to increased incidence of other cancers such as lymphomas, retinoblastoma and renal tumours (Figure 4) (17).



Figure 4. Estimated total incident cancer cases in 2015 by the top 15 specified diagnoses and region



Source: Adapted from Ward et al. 2019 (17).

- |                 |                    |                   |                 |                           |
|-----------------|--------------------|-------------------|-----------------|---------------------------|
| Eastern Africa  | Eastern Asia       | Caribbean America | Eastern Europe  | Oceania                   |
| Southern Africa | South-central Asia | South America     | Northern Europe | Australia and New Zealand |
| Western Africa  | South-East Asia    | Northern America  | Southern Europe |                           |
| Northern Africa | Western Asia       | Central America   | Western Europe  |                           |

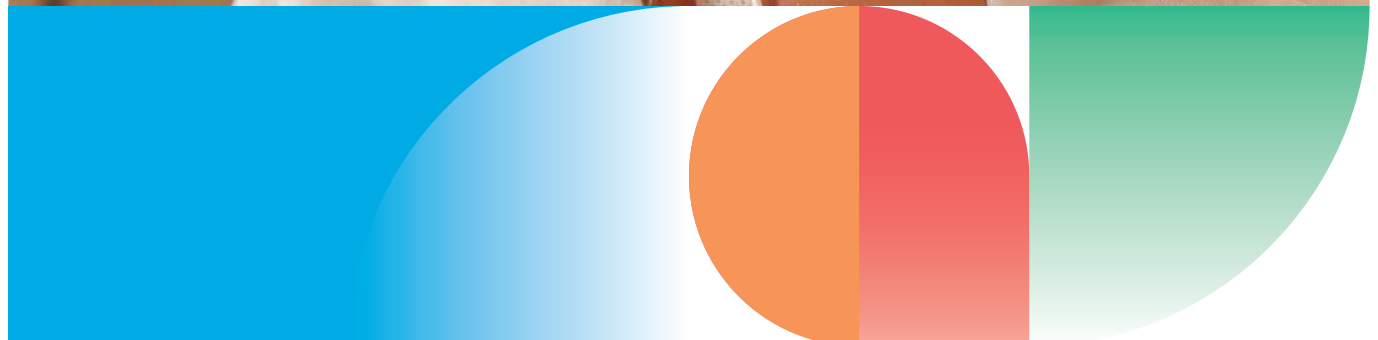
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More than 90% of children with cancer live in LMIC, settings where health systems are least prepared to manage the disease burden. The consequences are inaccessible care, avoidable deaths and social and economic hardship.

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Archivo AYUVI/ Unidad Nacional de Oncología Pediátrica -UNOP-



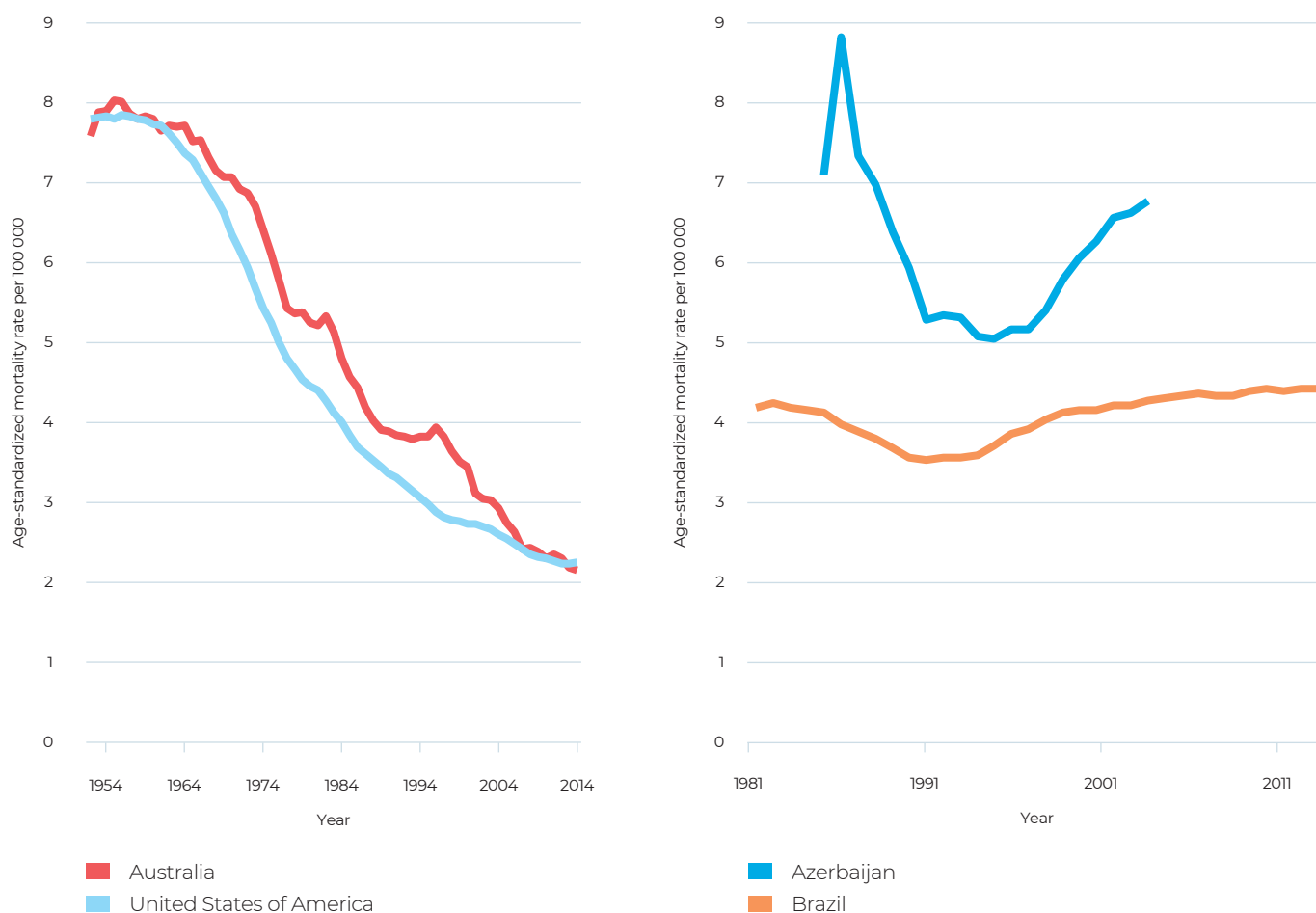
## CHILDHOOD CANCER MORTALITY

Cancer mortality data are often not well-linked to incidence data due to different data collection systems, leading to an underestimation of the actual mortality. Additionally, inadequate data availability in LMIC, does not allow for an accurate assessment of the cancer burden in children. However, available data in the WHO Global Health Estimates suggest that annual deaths from childhood cancer have been generally stable between 2000 and 2019 (22). In 2019, an estimated 100 000 children died of cancer (22). In 2019, childhood cancer caused an estimated 7.8 million DALYs worldwide, 97.4% of which were from years of life lost (YLLs) and only 2.6% from years

lived with disability (YLDs) (19). Comparing this to key adult cancers, 41.4 million DALYs were caused by tracheal, bronchus and lung cancer, 19.8 million DALYs by breast cancer, and 10.2 million DALYs by cervical cancer in 2019 (19).

Trends in childhood cancer age-standardized mortality rates (ASMR) demonstrate significant progress in high-income countries (HIC) related to improvements in survival (Figure 5). Rates in LMIC with high-quality information systems have shown that mortality rates have been stagnant. In some settings, ASMR have increased. This is likely related to increased quality in vital statistics with more accurate cause of death attributions as cancer becomes a recognized aetiology for children.

**Figure 5. Trends in childhood cancer mortality, comparing HIC with LMIC**



Source: WHO 2021 (25).

As the overall under 5-year old mortality rate decreases in lower-income countries and with improved capacity to diagnose childhood cancer, the number of incident cases of childhood cancer may also increase and cancer emerges as a leading cause of death for those younger than 20 years of age (22). In HIC, childhood cancer is the

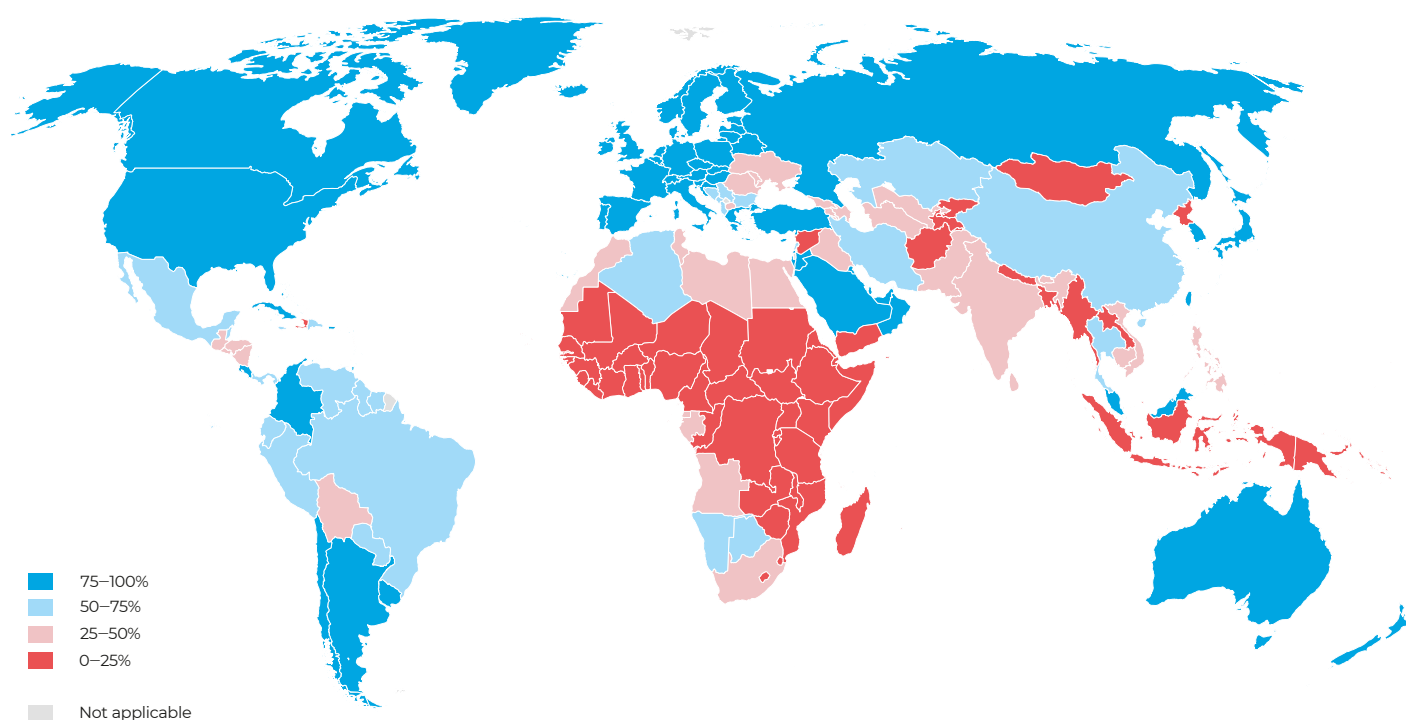
second leading cause of death for children aged 5–14 years (16). In the interim, a significant number of childhood cancer cases and deaths will be missed, reaching nearly 2.9 million between 2015 and 2030 according to some estimates (17).

## 1.2.2 CHILDHOOD CANCER SURVIVAL

The likelihood a child with cancer surviving is directly dependent on where that child lives, the socioeconomic status of the child's family and the underlying health system context. Survival probabilities range from over 80% in HIC to 50% in upper-middle-income

countries and less than 30% in LMIC and low-income countries (LIC) (Figure 6) (4,26–29). There is significantly variability in survival within middle-income countries and LIC and also among different sub-populations within those countries.

**Figure 6. Estimated childhood cancer 5-year net survival by country (2015–2019)**



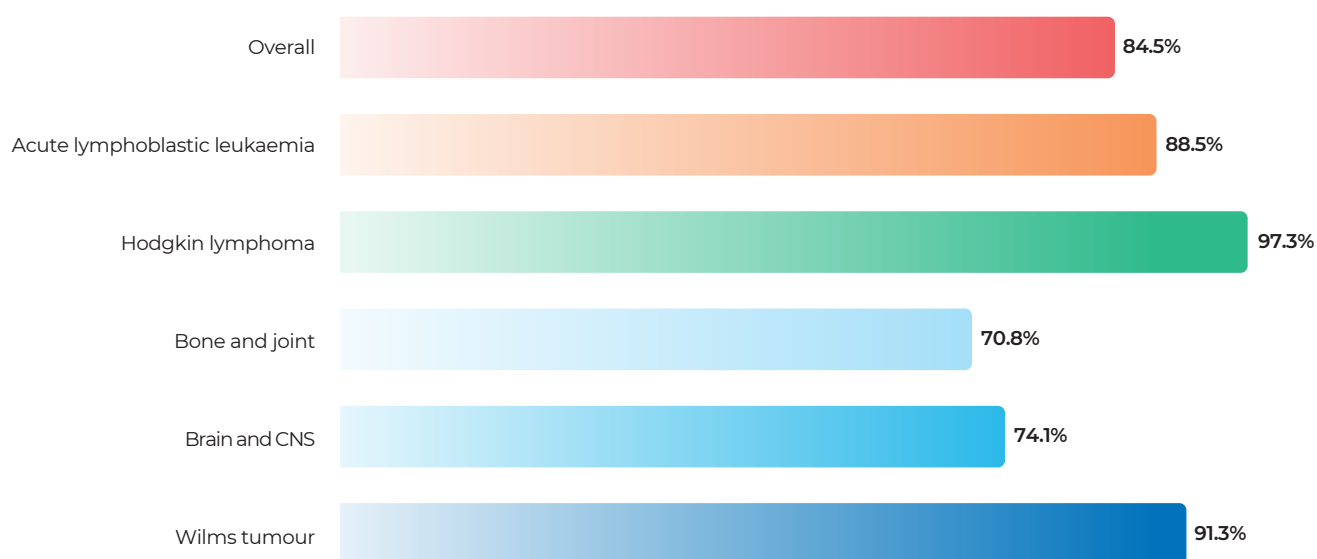
Source: Adapted from Ward et al. 2019 (26).

Inadequate data availability in LMIC, unfortunately, limits an accurate assessment of the cancer burden in children. Nonetheless, inequalities in childhood cancer survival are well documented and warrant a national and global response (Section 1.3).

Trends in survival diverge by setting and income level. For example, 5-year survival in the United States of America has reached

approximately 85%, having increased from 58% since the mid-1970s (Figure 7, Figure 8) (30). Progress in several countries has been even more remarkable, building on best practices learned in HIC. In Estonia, for example, the survival rate improved from 24% in the 1970s to 73% in the 2000s. This progress has been achieved through research, including cooperative group trials, improvement in quality and innovative approaches to care (31).

**Figure 7. 5-year survival rate for childhood cancers in the United States**

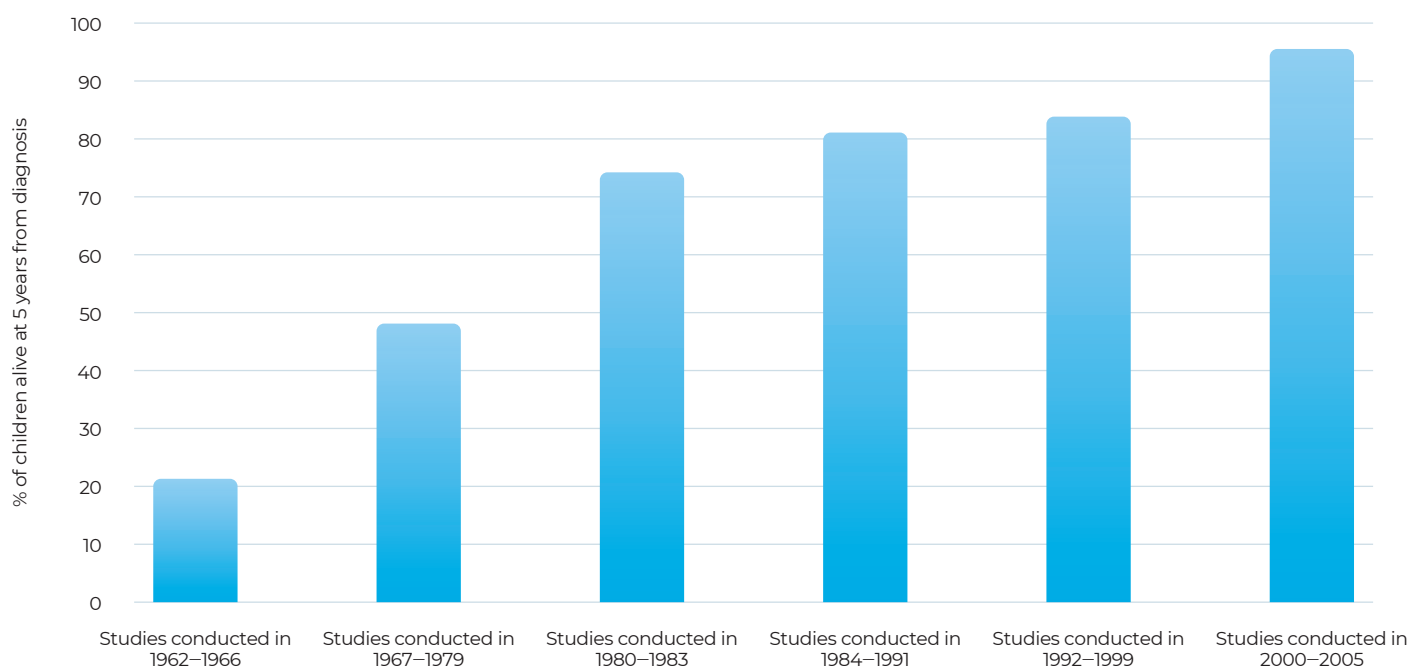


CNS: central nervous system  
Source: Noone et al. 2018 (27).

The majority of deaths from childhood cancer can be avoided through a public health approach to cancer control focused on UHC access to high-quality childhood cancer care and continuous

cancer surveillance. Investing in a set of essential, comprehensive interventions in childhood cancer control can achieve survival probabilities greater than 60% (Section 1.5).

**Figure 8. Improved survival for children with acute lymphoblastic leukaemia**



Sources: Adapted from Hunger and Mullighan 2015 (11); Pui 2006 (32).

## 1.2.3 ACCESS TO CHILDHOOD CANCER SERVICES

While the past two decades have seen scale-up of capacity in select LMIC, access to childhood cancer services remains limited in most LMIC and generally correlates with expenditure on health and broader health system capacity (6). There are currently no global data on the availability of childhood cancer services in different countries (33).

In the 2019 World Health Organization (WHO) NCD Country Capacity Survey, over 90% of HIC reported having all fundamental cancer diagnosis and treatment services, namely pathology services (laboratories), cancer surgery, chemotherapy and radiotherapy,

being generally available to 50% or more of the patients in need (Figure 9) (34). In comparison, 55% of LIC reported having none of these services available.

The proportion of countries with such services for children are estimated to be even lower given the added level of competencies and specificities required to care for children with cancer. For example, the availability of radiotherapy and complex surgical care for children is also contingent on paediatric anaesthesia, which is required for those services to be available and effective (see Sections 2.4.2 and 3.2 for palliative care).

**Figure 9. Percentage of countries with the availability of cancer services, by World Bank income group, 2019**



## 1.2.4 SOCIAL AND ECONOMIC IMPACT OF CHILDHOOD CANCER

Children with cancer and their families, both in HIC and LMIC, suffer short- and long-term psychosocial, emotional, social and economic consequences secondary to cancer and its treatment.

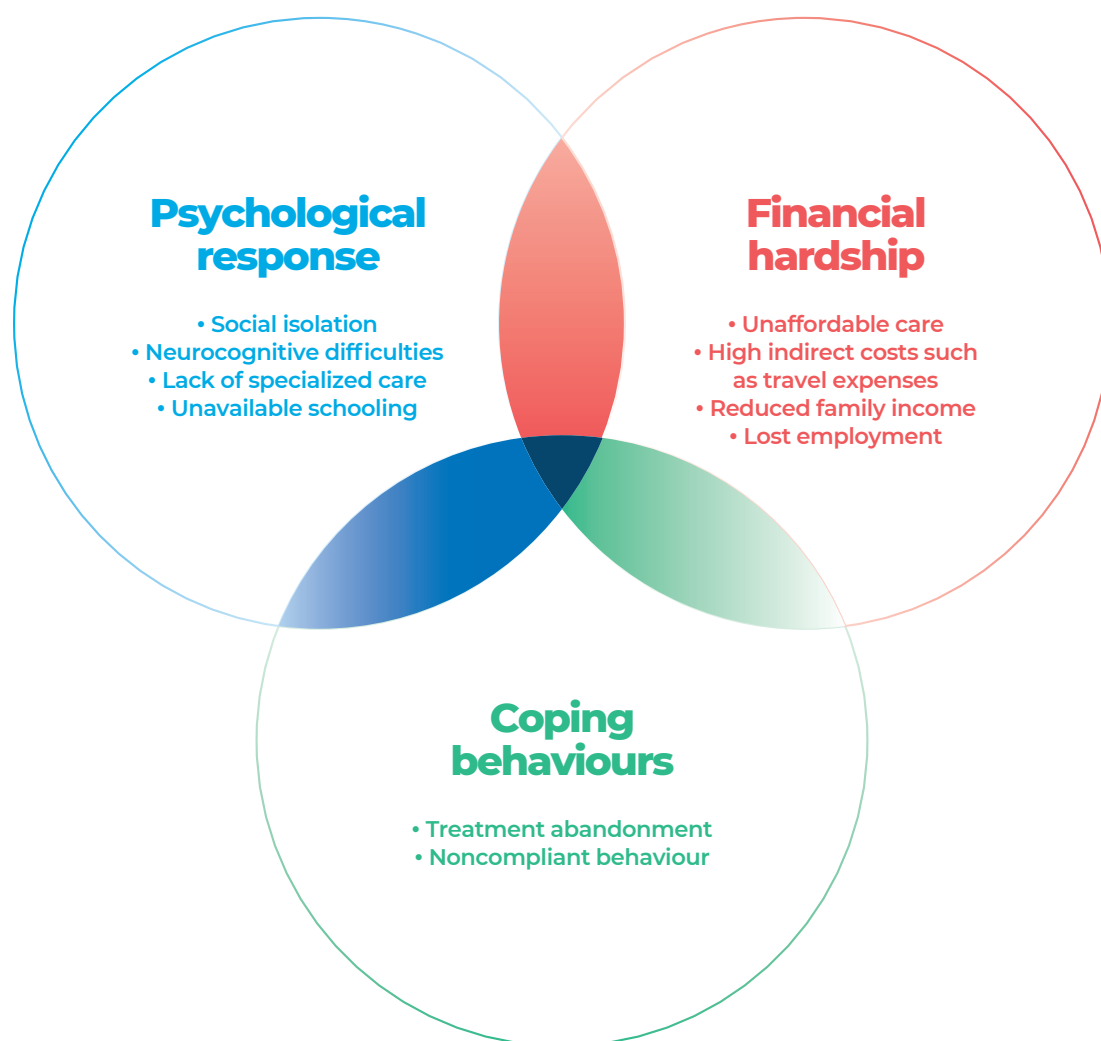
Families incur direct and indirect expenses related to childhood cancer care, creating three domains of financial hardship (material

conditions, psychological response, coping behaviours) (Figure 10) linked to the child, familial and economic impact of the disease (see Section 1.5). Direct costs can include travel to the cancer centre, payment for services and/or purchasing of products related to the care of their children. Indirect costs can also be substantial, such as reductions in their incomes due to interruption or loss of employment for parents (35). These result in negative short-term

effects on household earnings, including potential negative long-term effects on employment. When compounded by an inability to access financial assistance programmes, families can suffer significant financial hardship, including being pushed into poverty.

A Canadian study reported that the economic burden families faced during treatment has considerable long-term effects on the financial security, quality of life and well-being of the entire family, including siblings (36).

**Figure 10. Three domains of financial hardship impacting families in which a child has cancer**



Source: Nathan et al. 2018 (37).

Childhood cancer survivors may also suffer long-term financial and psychological, social and neurocognitive difficulties (with impact on educational abilities) (Figure 10) (38). This leads to increased difficulty with friendships and the need for special education, especially when reaching the adolescent years (39). Many of these difficulties can persist into adult years (40,41). The adolescent population is particularly sensitive to these effects, given the disruption in self-determination and gain of independence resulting in an enduring psychological impact (41). For this reason, this population requires specialized psychosocial care and follow-up after treatment.

**“Too many children have their lives cut short by cancer, and survival rates in poor countries are scandalously lower than those in wealthy countries.”**

— Dr Tedros Adhanom Ghebreyesus,  
WHO Director-General





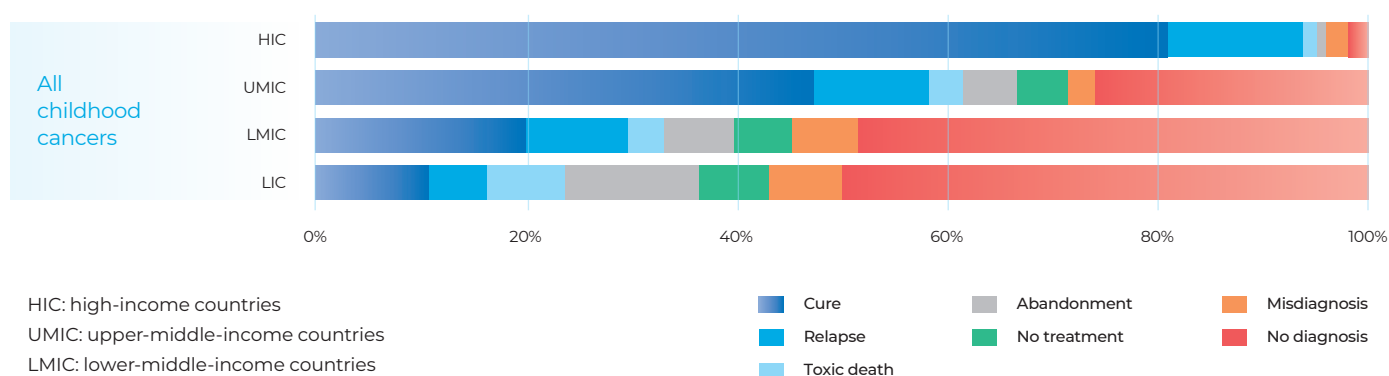
## 1.3 UNDERSTANDING THE CAUSE OF INEQUITY

The survival gap between HIC and LMIC (>80% compared to <30%) is one of the most profound health inequities across different communicable diseases and NCDs (Figure 11) (42).

It is important to understand the reasons for progress in HIC as well as root causes and barriers to achieving similar outcomes in LMIC. For select HIC and middle-income countries, implementation of

systematic interventions founded on research and innovation has driven improvements in care. These interventions include improvements in timely and accurate diagnosis, precise evaluation of disease extent, the ability to predict, stratify and tailor treatment intensity based on individualized disease factors and treatment response, the quality of disease-directed treatment, and supportive and survivorship care (Figure 11).

**Figure 11. Estimation of the factors contributing to lower survival in LMIC**



Source: Lam et al. 2019 (43).

For LMIC, the most common reasons for inferior survival are:

1. Cancer is **not diagnosed** because of the inability to recognize the signs of cancer, failure to access care or lack of diagnostic capacity. Diagnosis is **missed** or important details of the cancer are not established (such as subtype or staging) because of inadequate capacity or expertise.
2. **Delays in diagnosis or treatment** (resulting in more advanced disease) because of absence of referral pathways and/or relative lack of treatment capacity.
3. Variations in **treatment quality** or complexity or lack of supportive care services resulting in toxic death or relapse.
4. Treatment abandonment due to high costs, inadequate access to services or misconceptions on the part of caregivers.

The contributing factors are addressed through direct programmes and strengthened health systems using the pillars and enablers of the **CureAll** approach (see Section 3).



# 1.4 CHILDHOOD CANCER IN THE PUBLIC HEALTH AGENDA

Childhood cancer functions at the interface of two traditional public health sectors: cancer and child health. By strengthening health systems, effective childhood cancer control can accelerate progress towards attaining the United Nations 2030 Agenda for Sustainable Development, in particular health-related targets of achieving UHC (target 3.7) and reducing under 5-year-old mortality (target 3.2) and premature mortality (target 3.4), while also contributing to non-health related Sustainable Development Goals (SDGs) (Figure 12).

Childhood cancer control demonstrates the interconnectedness of the SDG agenda and, accordingly, requires multisectoral collaboration (SDG 17). Effective childhood control advances progress towards targets in reducing impoverishment (SDGs 1, 10), developing innovative models for education (SDG 4), promoting gender equity (SDG 5) and stimulating gainful employment and social stability (SDGs 8, 16). Progress in non-health related SDGs also contributes to successful childhood cancer control by ensuring improved nutrition (SDG 2) and promoting access to clean water and sanitation (SDG 6).

**Figure 12. Selected United Nations Sustainable Development Goals in close relation with childhood cancer**

	Financial protection from catastrophic illness like cancer reduces poverty		Universal access to clean water and sanitation can reduce rates of infection-related complications
	Reducing hunger and malnutrition improves childhood cancer outcomes		Investing in diverse occupations required for care stimulates local economic growth and employment
	Investing in childhood cancer supports attainment of multiple health related targets		Promote access to care for all communities to reduce catastrophic health expenditure and inequalities
	Educational services needed for children with cancer requiring prolonged hospitalizations		Investing in child health promotes social stability and reduces exploitation and discrimination
	Promote access to care that does not discriminate against girls and fosters mothers' overall well-being		Multisectoral collaboration and international cooperation improve childhood cancer outcomes

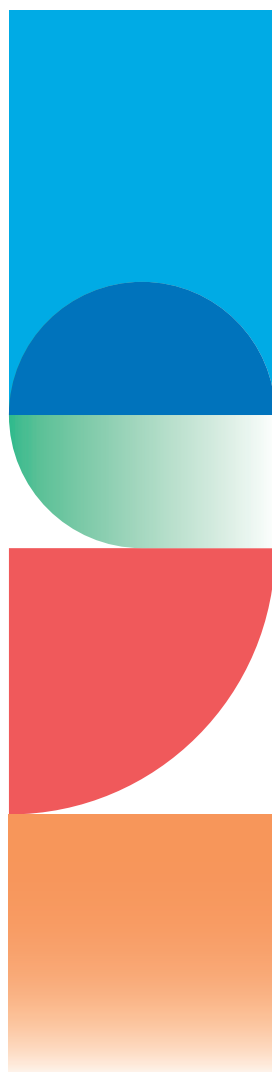
Source: WHO 2020 (7).



Dr. Mae Dolendo, Southern Philippines Medical Center/Children's Cancer Institute

## 1.4.1 GLOBAL COMMITMENTS TO CHILDHOOD CANCER

The current mandate and political foundation of childhood cancer as a priority in the development agenda have been specified in multiple commitments related to cancer and NCDs (Box 2). Delivering on these political commitments will bring improved health and well-being to millions of children around the world in the next decade.



Gabriel Alessandro Mayorga, survivor of acute lymphoblastic leukaemia





## Box 2. Context of the WHO Global Initiative for Childhood Cancer

*In September 2011, during the United Nations General Assembly High-level Meeting on the prevention and control of NCDs, a Political Declaration was made to address cancer prevention and control as well as other NCDs, which included a road map of national commitments from Heads of State and governments. This resulted in the adoption of the Global Action Plan for the Prevention and Control of NCDs 2013–2020 endorsed at the Sixty-sixth session of the World Health Assembly.*

*Recognizing the importance of childhood cancer to delivering on the NCD agenda, Member States, working with the International Society of Paediatric Oncology (SIOP) and Childhood Cancer International (CCI), convened a side event on childhood cancer during the 2015 World Health Assembly, highlighting the importance of universal access to treatment, care and support for children (Figure 13).*

*Commitment to childhood cancer accelerated with the adoption of World Health Assembly resolution WHA70.12 (May 2017) on cancer prevention and control (44). This resolution provides a clear commitment by Member States to prioritize the cancer agenda with childhood cancer as an important starting point and provides WHO with a mandate to lead the global cancer response (44). Similar commitments to cancer have been formulated at the regional level, where regional frameworks have been endorsed by the WHO Regional Committees for the Eastern Mediterranean Region and South-East Asia Region. The foundations of a global and regional response have been set.*



Figure 13. Key events related to the WHO Global Initiative for Childhood Cancer

**May 2015**

*World Health Assembly side event*

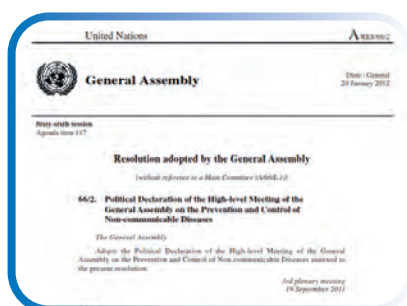


2

1

**September 2011**

*United Nations General Assembly  
High-Level Meeting on NCDs*





## September 2018

*United Nations General Assembly launch*

WHO announced the WHO Global Initiative for Childhood Cancer following the High-Level Meeting on NCDs

5

3

4

## August 2018

*Stakeholder meeting at WHO*

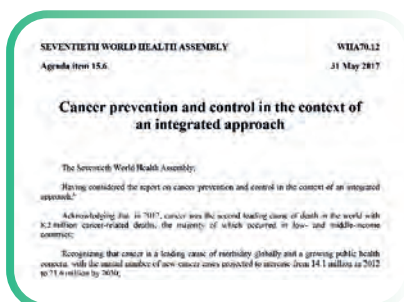
WHO Global Initiative for Childhood Cancer First Stakeholder meeting at WHO headquarters, Geneva



## May 2017

*World Health Assembly resolution*

Cancer prevention and control in the context of an integrated approach





## 1.4.2 GLOBAL INITIATIVE FOR CHILDHOOD CANCER

In August 2018, WHO convened the first Global Consultation on Childhood Cancer, which resulted in the WHO Global Initiative for Childhood Cancer in accordance with the WHO mandate and Member State commitments. Clear consensus emerged from the Consultation that investing in childhood cancer control is feasible, effective and sustainable, offering an opportunity to demonstrate success in NCD and cancer agendas.

In September 2018, WHO, alongside partners, launched the Global Initiative for Childhood Cancer at an inaugural side event on childhood cancer at the United Nations General Assembly third High-level Meeting on the prevention and control of noncommunicable diseases. The Initiative seeks to prioritize childhood cancer globally, nationally and regionally and to support governments in building high-quality and sustainable childhood cancer programmes, with a target of reaching at least a 60% survival probability at 5 years for children with cancer by 2030, while reducing suffering for all children with cancer (1) (Section 2.1).

This target represents a doubling of the current global cure rate for children with cancer and is achievable with broad political commitment, strategic investments and the development of strategic action plans led by governments and supported by individuals and partners from academic institutions and nongovernmental organizations, including parent support and advocacy groups to private sector entities and philanthropic foundations.

By achieving this target, the lives of an additional one million more children can be saved over the next decade.



## 1.5 INVESTMENT CASE

Inclusion of childhood cancer services in guaranteed health benefit packages is necessary to improve access to childhood cancer services and important to the attainment of UHC and other targets in the United Nations 2030 Agenda for Sustainable Development (see Section 1.4). Many countries are in the process of defining such packages that often involves the use of economic data to set priorities and define budgetary impact of different intervention options.

Quantifying the budgetary impact of childhood cancer informs dialogues on the justification of expenditure on specific health programmes as well as how it relates to expenditure in other sectors. Investment cases present both the expenditure on childhood cancer programmes and the health and broader economic benefits to justify investments in health. These documents facilitate discussions between health and finance ministries regarding increasing the health budget for better, more responsible use of government resources.



Brian Walusimbi, Bless a Child Foundation, Uganda

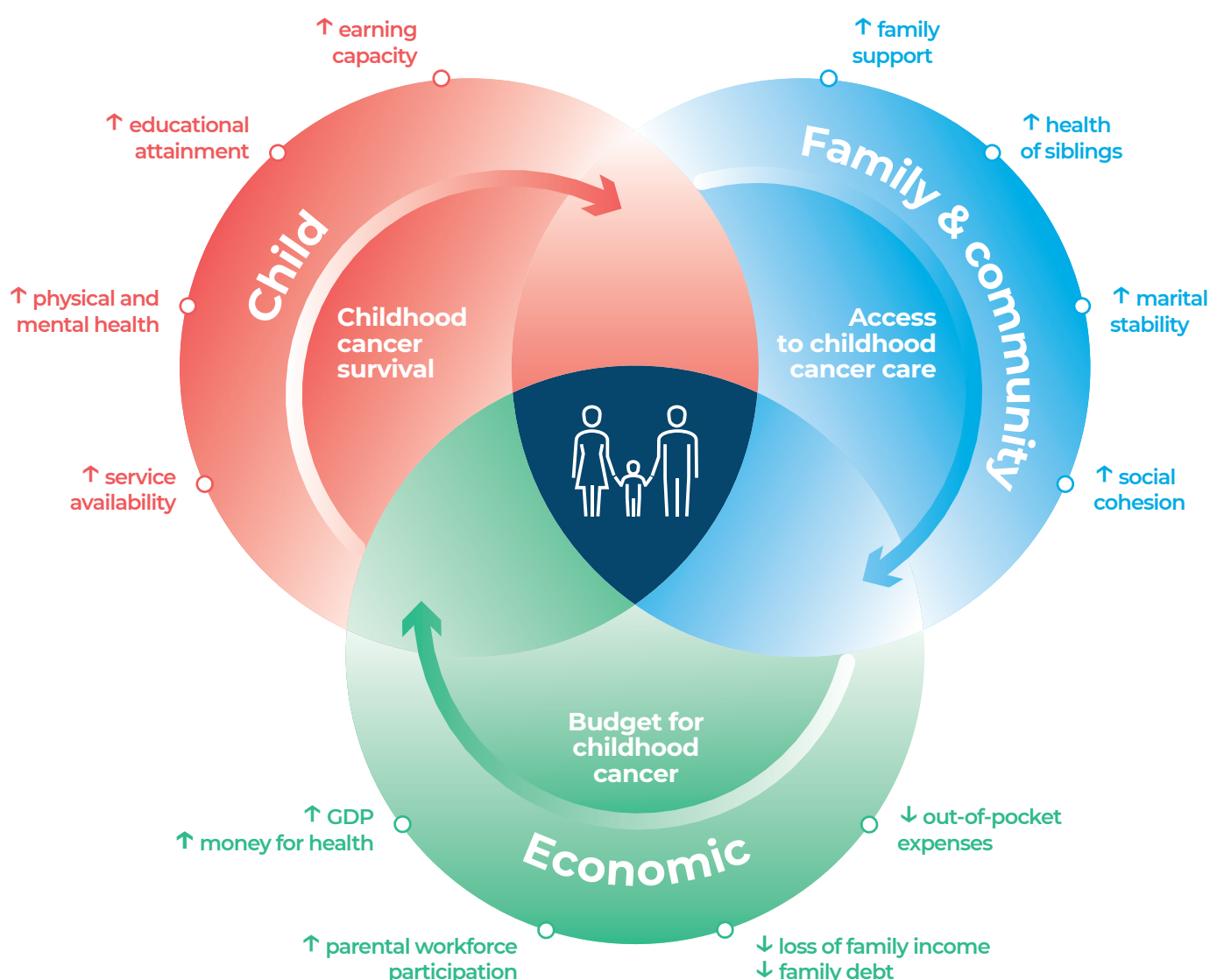


Over the past years, WHO has produced investment cases for cancer and NCDs in general (6,45). Scaling-up interventions in prevention and control of NCDs will yield a return to society of at least US\$7 in increased employment, productivity and longer life. Similarly, investment in cancer control programmes will have a positive return by 2030, yielding 7 million lives saved.

Investing in cancer, and childhood cancer in particular, outweigh the potential economic costs of cancer programmes. Each child who

dies prematurely as a result of cancer represents a loss to the family and threat to family cohesion that leads to a long-term societal loss impacting economic growth, workforce participation and human capital (Figure 14). Estimation of the economic gains of investing in childhood cancer are based on a revised version of the WHO tool for Economic Projections of Illness and Cost (EPIC), which estimates changes in rates of gross domestic product resulting from the implementation of health interventions on the size of the effective labour force and the impact of health expenditure (46).

**Figure 14. Economic and social value of investing in cancer and other NCD prevention and control interventions**



GDP: gross domestic product

Source: Adapted from WHO 2018 (45).

## 1.5.1 EVIDENCE OF COST-EFFECTIVE CHILDHOOD CANCER INTERVENTION

Multiple groups have shown the favourable cost-effectiveness of childhood cancer interventions and the value of investing in childhood cancer programmes (28,33,47). A review performed by the Disease Control Priorities-3 Cancer Author Group (DCP-3) estimated that the incremental cost per capita to treat selected childhood cancers in LIC is US\$ 0.03 and in upper-middle-income countries is US\$ 0.09, constituting the lowest budget impact for any of the estimated marginal costs of essential interventions in LIC from the DCP-3 cancer package (48). To date, however, many published estimates

have not accounted for key cost inputs required for diagnosis and multimodality treatment (47).

The recent Lancet Oncology Commission on sustainable care for children with cancer found that investments in childhood cancer to increase coverage and quality of care could avert 6.2 million deaths in children with cancer between 2020 and 2050 and generate global lifetime productivity gains of US\$ 2580 billion in 2020–2050. This would yield a net return of US\$ 3 for every US\$ 1 invested (33).

## 1.5.2 GENERATING AN INVESTMENT CASE IN CHILDHOOD CANCER

There are limited data on financing childhood cancer and no tools to support country-level decision-making to facilitate inclusion of essential interventions in national health benefit packages. Additionally, a review of 527 national cancer (or cancer-related) plans from 156 countries found that nearly 90% did not perform costing (49). To close this gap, WHO, in collaboration with the International Agency for Research on Cancer (IARC), developed a tool to support costing of cancer programmes and to produce national investment cases for cancer care with progressive tiers of essential service, framed by health system capacity (Box 3) (6).

The platform defines essential service, recognizing the specificities and comprehensiveness of childhood cancer care based on the **CureAll** framework. After an initial situational analysis, inputs that can be tailored to the country context include current and project coverage, type and complexity of interventions, treatment completion or aban-

donment rates, quality of care and stage of diagnosis or delays in care. Outputs include estimates on disaggregated costs per year; required health products, workforce, infrastructure such as inpatient hospital beds and others; and health benefits, including averted deaths and life years saved.

As a sample exercise for the Global Initiative for Childhood Cancer, a global scenario can be considered with baseline coverage at 40% and scale-up to 90% coverage, high-quality, complex childhood cancer services would require US\$ 0.14 per capita per year (50,51). Such strategic investments could yield at least 200 000 lives globally by 2030. Effective application of this tool allows for data-informed, evidence-based selection of interventions, priority setting, costing of national plans or benefit packages pages inclusive of childhood cancer and production of national investment cases through stepwise scale-up pathways.

### Box 3. Methodology for an investment case in childhood cancer

*In this model, the additional resources required globally to scale up cancer services have been estimated for the six tracer childhood cancers and are integrated with the broader cancer model that includes eight adult cancers. At three tiers of capacity (6), resource-stratified packages of care were estimated as a basis for a phased approach for implementing cancer control plans. Tiers are assigned according to a country's health system.*

*All costs associated with delivering care are included, regardless of who currently pays for them and are calculated using a bottom-up approach. Cost inputs (e.g. health workforce, equipment, supplies) required*

*to deliver an intervention were defined through a review of existing guidance documents on each tracer cancer and expert consensus. The quantity required for each input is estimated and the price sought from global databases, as previously described (6).*

*The health impact associated with scaling up the package of interventions is calculated in a multistage life-table model with epidemiological data for each cancer provided by the IARC Global Cancer Observatory database (15). Effect sizes associated with the scaling-up of interventions were derived from published studies and confirmed through expert consensus.*



Children with  
cancer can't fight  
alone, together  
we can fight it  
and win 🏆

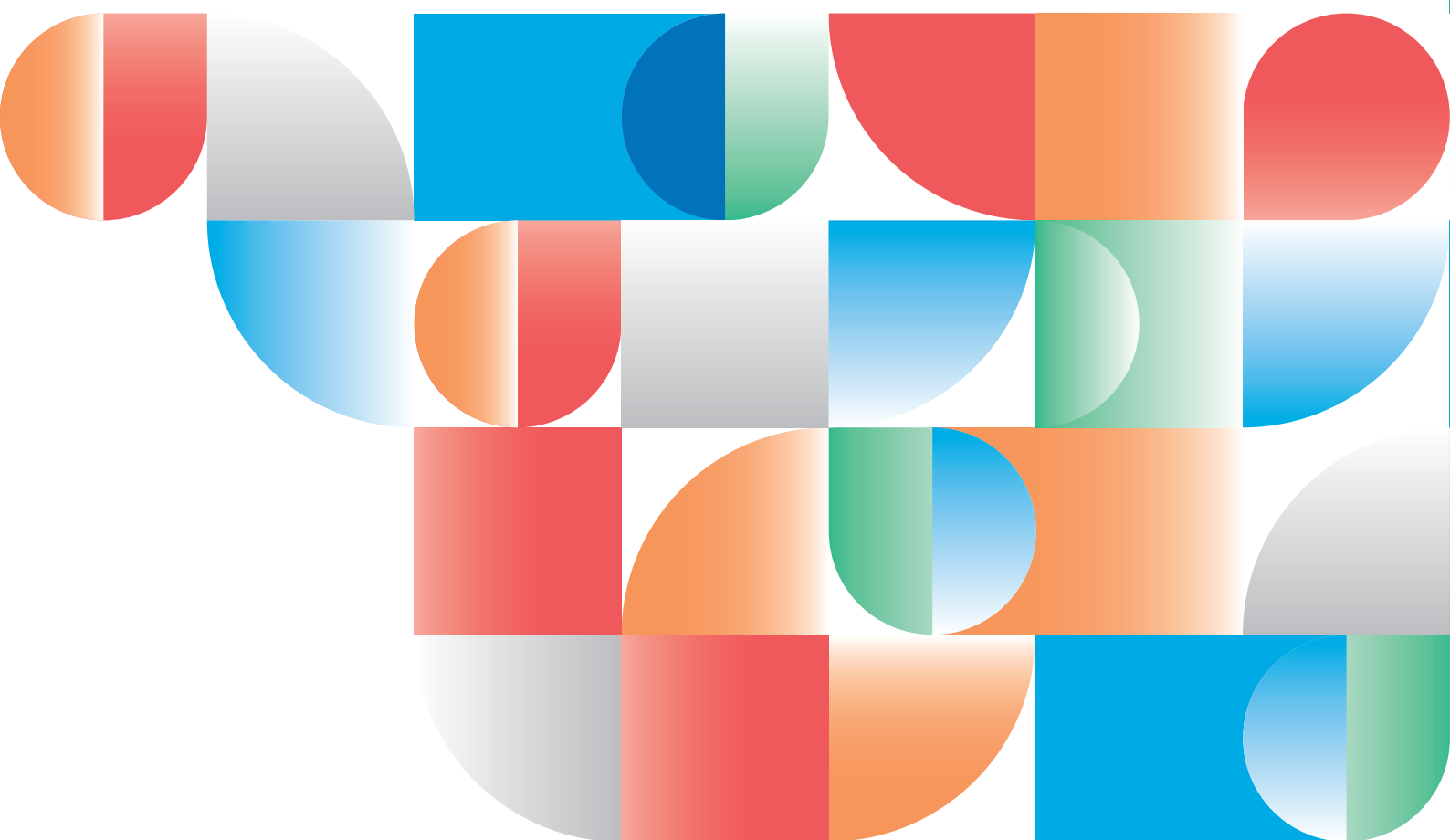
— Prince

Survivor of acute lymphoblastic leukaemia



## Section 2.

# Strategic approach of *CureAll*







## 2.1 OBJECTIVES OF THE WHO GLOBAL INITIATIVE FOR CHILDHOOD CANCER

To achieve the stated goal of increasing survival for children with cancer to at least 60% by 2030, improvements in access and quality of care are needed. The Initiative has two primary objectives:

1. Increase the capacity of countries to provide quality information and services for children with cancer; and
2. Increase prioritization of childhood cancer at the global and national levels.


These objectives are accomplished through concerted efforts at the global, regional and national levels with distinct expected outputs and activities (Figure 15).

By early 2021, 15 countries had committed to implementing the Initiative and many more have participated in regional or subregional networks (Box 4, Box 5). This framework document, delineating the **CureAll** approach, has been developed to guide countries as they implement the Global Initiative for Childhood Cancer (see the Purpose, Scope and Audience section).

**Figure 15. Goal, objectives, outputs and activities of the Global Initiative for Childhood Cancer**

Goal	By 2030, achieve at least 60% survival for childhood cancer globally and reduce suffering for all		
	Save one million additional lives		
Objectives	<ol style="list-style-type: none"> <li>1. Increase capacity of countries to provide quality services for children with cancer, and</li> <li>2. Increase prioritization of childhood cancer at the global, regional and national levels</li> </ol>		
	Implemented across 6–10 countries (by 2019–2020) and 18–25 countries (by 2021–2023)		
Outputs & activities	National	Regional	Global
	Country assessment, case studies, support and implementation plans	Regional assessment and dialogues, snapshots and policy briefs	Global framework, technical package, dashboard and advocacy materials





Rodrigo Gaitán, AYUVI/Unidad  
Nacional de oncología pediátrica, Guatemala

#### **Box 4. Peru: focus country committed to action**

*Peru was designated as a focus country in June 2019, aligning with the Initiative's target of reducing morbidity and mortality from cancer in children. To achieve this goal three main lines of action were defined: improve early detection; implement information systems for children and adolescents; and improve the quality of childhood cancer care.*

*Acceleration of the implementation of the **CureAll** framework was possible through the development of an appropriate governance structure and coordinated country-level actions based on capacity-building and teamwork. Political will was transformed into legislation by the creation of the National Childhood Cancer Law in September 2020.*

*To date, Peru has formed working groups to strengthen and integrate around 10 priorities. Starting with basic education of the primary care providers and building a network of care, five institutions in five cities of Peru were consolidated as tertiary and secondary care. Multidisciplinary care members joined efforts to build the educational skills of their staff and obtained accreditation for the centres. The major centres in Lima will serve as quaternary centres and educational hubs. Statistics from the six index cancers were acquired. The situational analysis showed that in order to improve outcomes, special consideration should be given to prevent abandonment of therapy, build an oncology trained nursing staff, address infection control and scale-up specialty surgical services (oncology ophthalmology and reconstructive orthopaedics).*

Source: Vasquez et al. 2021 (52).

## Box 5. Childhood Cancer Network in the WHO South-East Asia Region

The South-East Asia Childhood Cancer Network was organized in July 2020 to provide a platform for service providers, policy-makers and advocates to facilitate discussions, share experiences and allow for broader collaboration. This will ultimately catalyse changes leading to an increase in access and improvement in quality of care for children with cancer in the region. Currently, the network has 15 member institutions from 10 Member States, representatives from the relevant division or unit of the Ministry of Health, community-based organizations and WHO country offices.

The Network also promotes bilateral collaboration among member institutions. One such example is a horizontal model of learning and training between a Jakarta's member institution and another member in Timor Leste to enable establishment of childhood cancer services. Many more such collaborations are in consideration and some of them are expected to materialize very soon.

The South-East Asia Childhood Cancer Network is expected to bring impact through multiple components of the **CureAll** approach.



The Initiative seeks to serve all children with cancer, not only those in a particular region or with select cancers, but also children around the world, by promoting best practices, advancing access and facilitating innovation. All governments and stakeholders can benefit by participating in the Initiative. In HIC, for example, the **CureAll** approach can be used to monitor and manage inequities among disadvantaged populations or to more effectively manage long-term toxicities of therapies.





## 2.2 CureAll FRAMEWORK: PILLARS AND ENABLERS

The main conceptual approach of **CureAll** is to provide governments and stakeholders with a framework for action that strengthens capacity across the health system and along the entire patient journey (or cancer care continuum), ultimately delivering improved outcomes for all populations. The **CureAll** framework does this by outlining programmes and priority interventions grouped under four pillars of action (referred hereafter to as “pillars”) and three enablers.

The four **CureAll** framework pillars:

- **C**entres of excellence and care networks with a sufficient and competent workforce to increase capacity to deliver quality patient-centred services.
- **U**niversal health coverage by integrating childhood cancer as part of the full range of essential quality-assured services and included in benefit packages.
- **R**egimens and roadmaps for diagnosis and treatment that are context appropriate and facilitate delivery of quality services through evidence-based utilization of essential health products.
- **E**valuation and monitoring, with robust information systems

and research to ensure effective implementation, coupled with research on the unique genetic, epigenetic, environmental and societal aspects of childhood cancer in different populations.

The three **CureAll** framework enablers constituting the mechanisms that support health systems to improve their access to and quality of care are (see Section 3.5):

- **A**dvocacy
- **L**everaged financing
- **L**inked governance

Success in the implementation of the **CureAll** framework can be achieved through collaboration among multiple sectors. Mobilizing stakeholders to support governmental efforts to accelerate progress represents a key factor for success.

The four pillars and three enablers facilitate broader health system strengthening efforts through alignment with the health system building blocks (Table 1).

**Table 1. CureAll alignment with health system building blocks**

<b>C</b>	Centres of excellence and care networks	Service delivery, health workforce
<b>U</b>	Universal health coverage (UHC)	Health financing, service delivery
<b>R</b>	Regimens for management	Access to health products
<b>E</b>	Evaluation and monitoring	Health information systems
<b>A</b>	Advocacy	Service delivery, health workforce
<b>L</b>	Leveraged financing	Health financing
<b>L</b>	Linked governance	Governance and leadership

The process of implementing the **CureAll** pillars and enablers requires four coordinated steps: (i) assess; (ii) plan, cost and finance; (iii) implement; and (iv) monitor and modify (see Section 4). Though addressing each pillar and enabler requires distinct activities along the assess–plan–implement–modify pathway (see Section 3), synergies can be captured when operationalizing these actions. Accordingly, implementation strategies should identify opportunities for integration and coordinated service delivery across all levels of the health system (see Section 4) and along the childhood cancer care pathway.



## 2.3 TRACER CANCERS

Six cancers have been selected as tracers for implementing programmes and monitoring progress in childhood cancer across the health system (Table 2). Each cancer was selected for a precise purpose to help inform a broader response relevant to all childhood cancers. Their inclusion does not suggest greater importance, but rather the ability to help monitor overall progress. Indeed, achieving the goal of the Initiative will require investments in and attention to all childhood cancers.

All six cancers have unique characteristics and are highly curable with proven therapies, together representing 50–60% of all childhood cancers.

**Table 2. Six common cancers for initial focus of the Global Initiative for Childhood Cancer**

Cancer	Justification	5-year overall survival rate with proven therapies
Acute lymphoblastic leukaemia	Prevalence: most common childhood cancer	86%
Burkitt lymphoma	Promotes equity: common in many LMIC and among HIV positive individuals	90%
Hodgkin lymphoma	Life course: common in adolescents	95%
Retinoblastoma	Integrated approach: connects communities for early diagnosis	96%
Wilms tumour	Highlights multidisciplinary care	90%
Low-grade glioma	Multisectoral interventions, representative of the second most common childhood cancer group, diverse workforce requirement	>85%

*Sources:* Adapted from Jones et al. 2018 (53); Minard-Colin et al. 2015 (54); Friedman et al. 2014 (55); Gatta et al. 2014 (29).



Elizabeth Whittington, St. Jude Children's Research Hospital

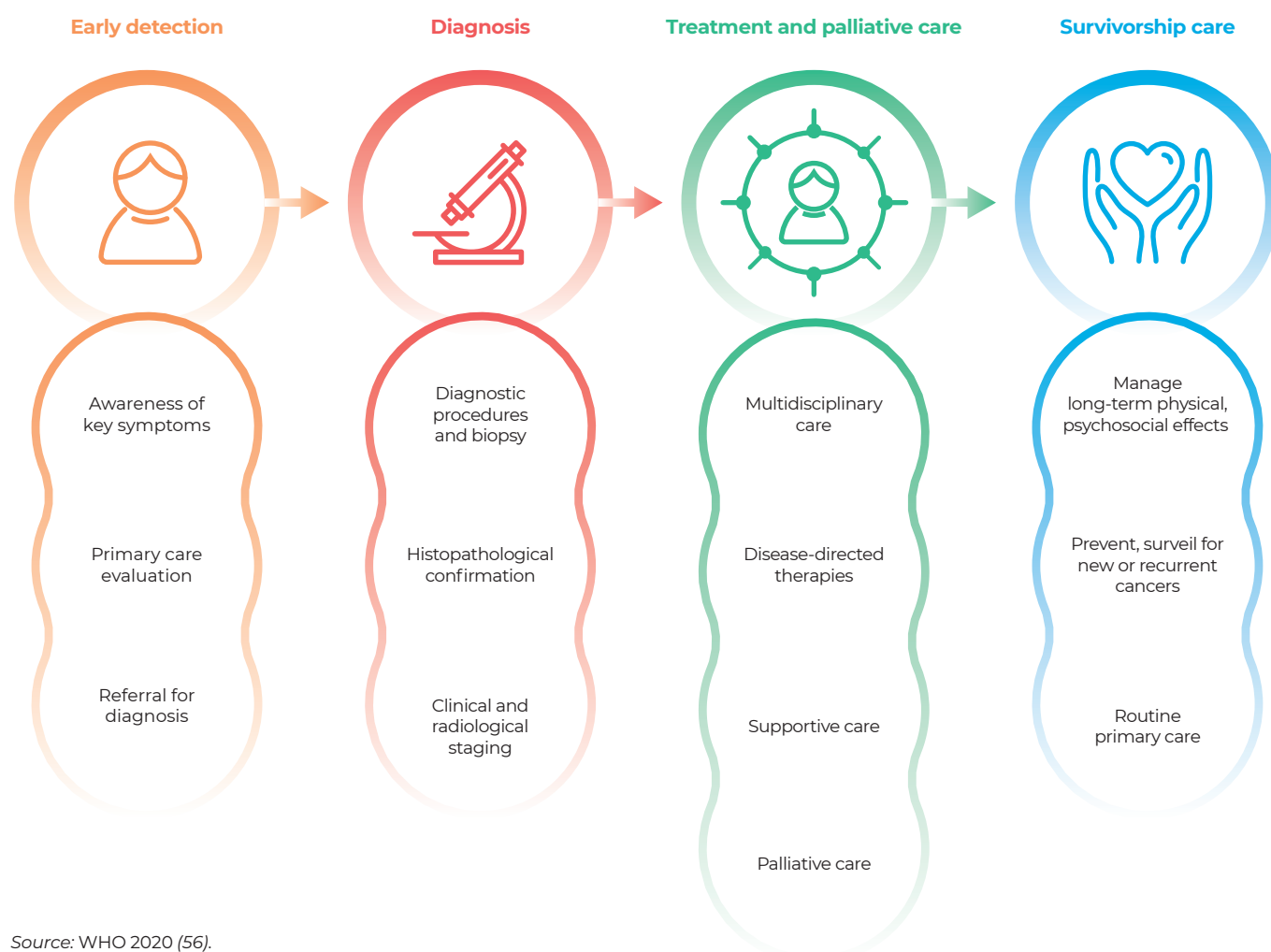


## 2.4 CHILDHOOD CANCER CARE PATHWAY

Understanding the childhood cancer care pathway, from symptom onset through diagnosis and treatment and ultimately to survivorship or end-of-life care, is important for the successful implementation of the **CureAll** approach. Health systems must be prepared to

respond to the needs of children along the entire pathway through coordinated services, the provision of multidisciplinary care and information systems that identify challenges at each step (Figure 16).

**Figure 16. Childhood cancer care pathway**



Source: WHO 2020 (56).

Caring for children with cancer carries unique specificities along the cancer continuum that must be included in packages of essential interventions in order to meet children's needs. These include:

**Early detection**, including primary care: careful attention to signs and symptoms in young children who cannot always describe symptoms; parents as well as primary care providers must be aware of the specific signs in order to achieve early diagnoses including timely diagnosis and staging.

**Diagnosis:** providers with specialized physicians with paediatric oncology training, imaging services, surgeons, pathology; consideration for general anaesthesia to perform diagnostic imaging (e.g. CT, MRI, nuclear medicine) and invasive diagnostic procedures such as for obtention of diagnostic tissue (e.g. lumbar puncture, bone marrow aspirate and biopsies, interventional radiological biopsies).

#### **Treatment:**

- Child-centred care: coordinated family centred-care with socioeconomic assistance that may include lodging house, transportation and food subsidies.
- Systemic therapy, with adequate supportive care and symptom management, including anti-emetic support during chemotherapy, which may include addressing anticipatory nausea, particularly in older children and adolescents.
- Surgery and anaesthesia: robust technical expertise according to disease indication and avoiding long-term morbidity when possible, such as avoidance of amputation. Trained providers in paediatric anaesthesia are also required.
- Radiotherapy: prescribed and delivered to reduce long-term toxicities. Radiotherapy often requires general anaesthesia for children unable to remain still.
- Medical supportive care: therapies can cause toxicities requiring immediate interventions to optimize outcomes and reduce treatment abandonment. These interventions include ensuring adequate nutrition, infection prevention and control, symptom management such as pain and nausea, and timely access to a blood bank, avoidance of organ injury and rehabilitation services (physical, cognitive and psychological). Fertility preservation must also be discussed with the child and family.
- Social and educational development: supporting school and having access to play and developmental activities throughout periods of hospitalization is particularly important and can be provided with in-hospital schooling programmes, dedicated play areas, play therapists and music/art therapies, among others.
- AYA care: consideration should be given to the specific characteristics and needs of this population (see Section 2.4.1).
- Psychosocial care (short- and long-term): families need a

psychosocial and economic evaluation and access to a psychosocial team to provide support, aiming to prevent refusal or abandonment of therapy. Psychosocial care should be adapted by age group, with particular attention to the AYA group, and be delivered by multidisciplinary psychosocial professionals (see Section 2.4.1).

#### **Palliative care and pain relief:**

- Palliative care should be offered early in the child's journey to provide relief of pain and all other types of suffering, physical and emotional, and also to support families. Distinct competencies are required for childhood-specific providers and services (see Section 2.4.1).
- Appropriate pain relief following procedures, this may include procedural anxiety. Support can be provided with play or music therapy using distraction techniques, role play and pharmacological support when appropriate.

**Survivorship:** children's lifespan after a cure from cancer is expected to be long, and as such the potential for long-term toxicities must be considered and discussed with families throughout all decision-making processes around cancer treatment, including risk of second malignancies, cardiovascular health, mental health and fertility preservation.

When implementing childhood cancer services, essential services must be defined according to the type of cancer, the stage at diagnosis or risk group and health system context across the cancer continuum. Such comprehensive services include psychosocial and nutritional support, infection prevention and control, blood banking services, resources to prevent and address oncological emergencies and financial support for the family. Considerations of sociodemographic and cultural factors are required to deliver comprehensive cancer care to children.





## 2.4.1 FAMILY-CENTRED, MULTIDISCIPLINARY CARE

### CHILD AND ADOLESCENT HEALTH SERVICES

**Nursing:** Studies in countries of all income levels have found that interventions that scale up nursing capacity through education and/or have sufficient nursing staff contribute to improved quality of care and reduced mortality (57,58). Nursing personnel should possess specialized competencies of paediatric oncology care to deliver the complex needs of children with cancer. Such trained staff should be optimized to deliver to the fullest extent of their training and accreditation, working on childhood cancer wards and avoiding unnecessary rotation, when possible, to ensure continuity of care and in-service training (59). Inadequate nursing staff or failure to possess the necessary competencies can limit quality of care even if other health professionals are present.

**Psychosocial support:** Addressing the emotional and behavioural needs of children, adolescents and their families throughout the course of disease (diagnosis, treatment, re-entry to school and community, end-of-life care and survivorship) to enhance coping and reduce suffering constitutes an essential component of the multidisciplinary approach (38). With parents' permission, it is important to include children in conversations and decisions about their treatment when it is age-appropriate, and that toolkits are available to facilitate the dialogue (60,61). Adolescents, in turn, should always be given an opportunity to discuss health matters with their providers privately, without the presence of family members, and should be offered private spaces within the hospital where possible for peer and social interaction, and for age-appropriate activities (e.g. music, games). Their voices and opinions should be a central part of the decision-making process.

Strong psychosocial care has been shown to prevent abandonment of treatment, reduce misperceptions or fears about treatment and ultimately contribute to improved outcomes (62). Supplementing psychosocial care with the provision of transportation and housing support enables families to attend appointments and adhere to prescribed treatment (63).

The AYA population has psychosocial needs during a period of growing independence from their parents, where they experience body changes, the development of self-image and sexuality. They start "discovering" the world, which can lead to behaviours such as alcohol and drug consumption, smoking and unsafe sexual behaviours that need to be addressed in an open and honest manner. It is also a period filled with opportunity to pursue projects (e.g. final school years, first jobs, thoughts about future career, first relationships). Particular attention should be paid to social well-being and to connectiveness with peers. As such, AYA psychosocial

needs should be evaluated and care should be adapted and, when possible, delivered by providers possessing specific competencies in the care of AYA.

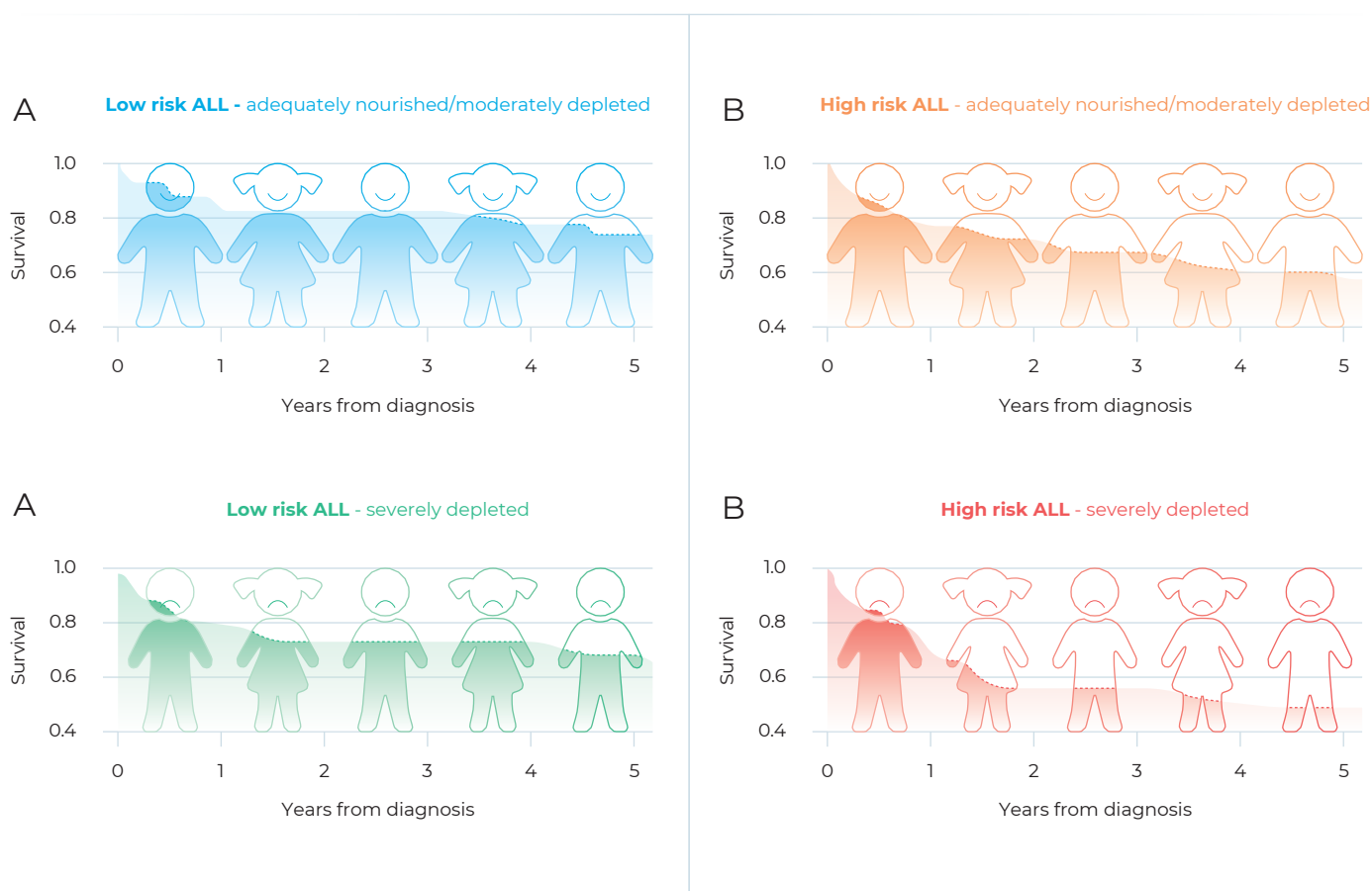
**Education/schooling:** Allowing children to pursue their schooling is important to maintain educational progress through cancer treatment, which often extends for months or years. In addition, schooling supports emotional and social development for children. Attending the classroom allows children to socialize with their peers, which helps them cope with treatment. This can be managed by employing teachers in-hospital to deliver group learning sessions and assist with tasks, liaising with patients' schools to increase the amount of support given and expanding online access to classroom lessons, including contact with peers. Attendance in school should be encouraged by medical professionals during periods of treatment where it is medically safe. For adolescents, this is particularly relevant as young people approach the end of their schooling and may face the challenges in completing important examinations and delays in preparing for higher studies or entering the professional workforce.

**Nutrition:** The vast majority of children with cancer live in LMIC where endemic rates of undernutrition remain a public health crisis (64,65). Globally, poor nutritional status in children with cancer (undernutrition or obesity) increases the risks of infection and treatment-related toxicities and is associated with increased rates of abandonment (Figure 17) (66–68). Assessment of the nutritional status at diagnosis should be conducted by a trained nutritionist or nurse and consider the recovery and age of the child. Moreover, reversal of these adversities can be achieved with the use of locally made, ready-to-use therapeutic foods (RUTF) as well as proactive nutrition interventions (69). These are readily available, effective and inexpensive.

The development of a national network with centres of excellence and communication systems and shared resources linked to regional centres allows for standardization of the interventions needed to address nutrition. The prospective recording of patients' nutritional status is essential to prevent and address the undernourishment secondary to receiving chemotherapy, which is related to mucositis, nausea, change of taste, among other factors. Established guidance documents with algorithms for nutrition management are available (70,71).

Nutrition education, an inexpensive approach to medical nutrition therapy, is also an important feature of nutritional programmes aimed at resolving malnutrition, particularly the double burden of malnutrition (overnutrition and undernutrition) that is an emerging chronic disease in most LMIC.

**Figure 17. Effects of nutrition intervention on survival**



ALL: acute lymphoblastic leukaemia

Source: Antillon et al. 2013 (65).

**Infection prevention and control:** Poor infection prevention and control, especially in the setting of malnutrition, can contribute to higher rates of infection-related mortality, leading to inferior survival rates for children with cancer in LMIC (72,73). Successful models of collaboration to improve infection control by implementing low-cost interventions and standard tools (for example, the WHO Hand Hygiene Self-Assessment Framework) contribute significantly to reducing the incidence of infection-related mortality in paediatric oncology centres (Box 6) (74). Currently, emerging infections, and increased resistance to antimicrobials, threaten us all, but particularly children. Thus, infection control and responsible use of antimicrobials should be implemented through infection stewardship.

## Box 6. Improvement strategy on infection and prevention control standards in Pakistan: multisectoral collaboration

Infectious complications represent a common cause of treatment-related mortality, particularly in LMIC. In Pakistan, an effective infection prevention and control programme was implemented at Lahore Children's Hospital through a multisectoral collaboration. A needs assessment evaluation was performed using an assessment tool from St. Jude Children's Research Hospital and WHO hand hygiene modules. Data-driven interventions were implemented to improve the inadequate practices responsible for high rates of health-related infections and included renovation of the Paediatric Oncology Unit with governmental funds and support from a grant given by the My Child Matters programme. Institutional collaboration also enabled training, education and improvement of personnel's practices to achieve infection prevention and control standards. This model of multisectoral engagement to implement infection prevention and control programmes can be replicated to contribute to reduce the infection-related morbidity and ultimately improve survival.

**Adolescents and young adults (AYA) care:** AYA is a distinct, vulnerable group with unique needs that are often underrecognized and overlooked by health care providers. Unmistakably, the epidemiology of cancer is different in this age group (see Section 1.2). In addition, histological types, tumour genomics, biology and clinical behaviour of common childhood malignancies may differ in adolescents compared with children. This is also reflected in different outcomes and survival in adolescents and children: survival rates in adolescents have not seen the same rate of improvement as in children. In some tumour types such as acute lymphoblastic leukaemia, survival for AYA is poorer than in younger children, due to different, more aggressive tumour biology, but also related to treatment choices. Models of care for AYA patients depend on country context, though select evidence has shown AYA patients with acute lymphoblastic leukaemia benefit from the choice of paediatric treatment protocols (75) and, in some settings, may also benefit from care in paediatric centres (76).

For cancer therapies, the physiology changes during the adolescent years affected by hormonal and other drivers may impact on drugs toxicity (77). However, as growing independent adults, the sense of invulnerability may cause them not to comply with therapy and are thus at higher risk of relapsing (78).

Young people's opinions must be encouraged and integrated into the decision-making process. Ideally, facilities have age-appropriate areas of care for AYA, allowing for privacy, social interaction and age-appropriate learning and developmental activities. AYA-specific cancer research is required to better understand the diseases in this age groups, and participation in AYA clinical trials must be encouraged, when available, to improve knowledge and outcomes. Transition to adult medical teams must be done respectfully and with attention to the adolescents' needs.

## 2.4.2 PALLIATIVE CARE

According to WHO, palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family. Since many children die today of cancer, the relief of suffering is central. Palliation not only heals, but also increases the betterment of communication between the child, parent and family, thus (79):

- Palliative care begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease (80). It is a combination of measures, notably related to symptom management, which contribute to maximizing health-related quality of life.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- Palliative care can be provided in tertiary care facilities, community health centres and children's homes.

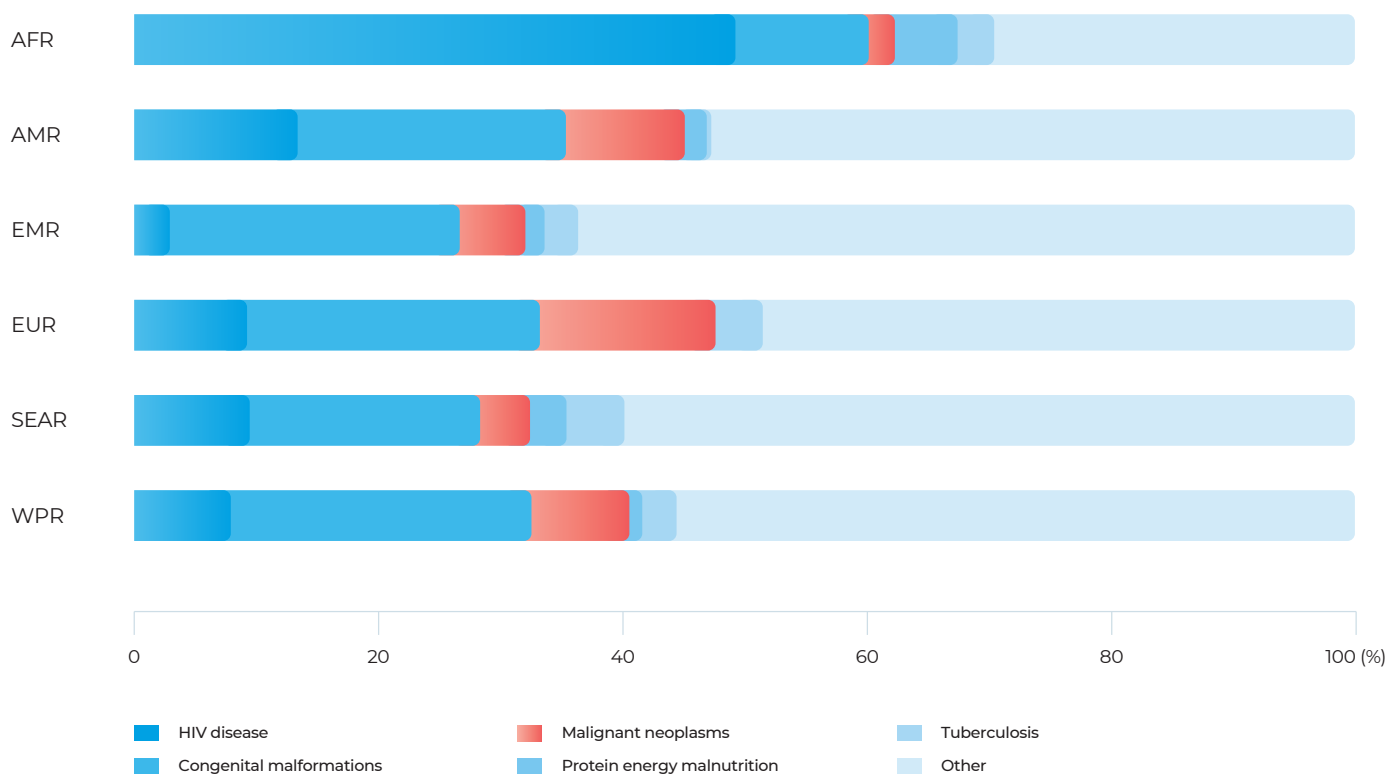
Bereavement support for parents whose children die from cancer is also an indispensable element of family-centred care, assisting the family (including survivor siblings) as they recover from the loss of a child.

According to the Lancet Commission report on global access to palliative care and pain relief, approximately 2.5 million children

die in need of palliative care and pain relief (81). Estimates from the Global Atlas of Palliative Care at the End of Life reveal that children with cancer are a significant contributor to the need for palliative care in LMIC (Figure 18) (82).



**Figure 18. Global need for palliative care in children by WHO region, major causes**



AFR: African Region; AMR: Region of the Americas; EMR: Eastern Mediterranean Region; EUR: European Region; SEAR: South-East Asia Region; WPR: Western Pacific Region

Other category includes: haemorrhagic fevers, dementia, inflammatory diseases of central nervous system (CNS), degeneration of CNS, cerebrovascular diseases, non-ischaemic and chronic ischaemic heart diseases, lung diseases, liver disease, renal failure, premature birth and birth trauma, injury, poisoning and external causes, arthrosclerosis and musculoskeletal disorders.

Source: Worldwide Palliative Care Alliance 2020 (82).



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Strong political commitments to palliative care exist, including, for example, World Health Assembly resolution WHA67.19 (May 2014) urging Member States to integrate palliative care as an essential component of their health care systems, and the inclusion of palliative care in the UHC packages of essential services (83). However, progress in increasing access to palliative care services is slow, and millions of children still lack access to palliative care (82,84). In a study evaluating the early impact of resolution WHA67.19, significant gaps remained between policies and their effective implementation, particularly in the realms of medicine availability,

delivery of education and benefits to the patients in need of palliative care (85).

Priority actions should be considered, including training of the workforce at all levels of care that address access to essential medicines and technologies, including paediatric formulations and opioid analgesia for pain management (oral and parenteral), medicines for other symptoms control and nutritional support, and psychosocial and bereavement support.

## 2.4.3 SURVIVORSHIP CARE

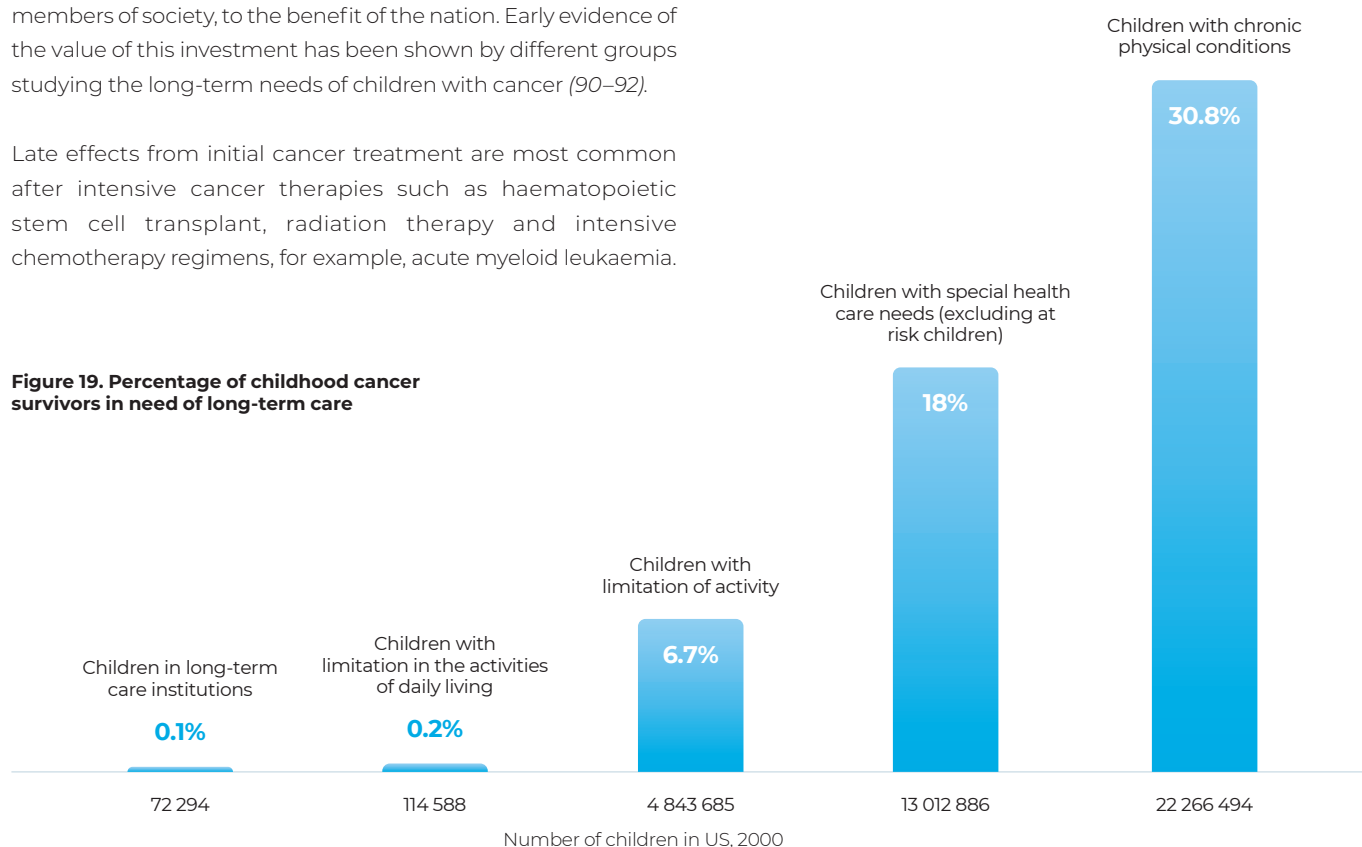
As a result of the considerable improvements in prognosis and reduction in mortality from childhood cancer, strategies are needed to reduce long-term toxicities and disabilities, such as cardiovascular disease and other chronic health conditions, secondary malignant neoplasms, and psychosocial and neurocognitive long-term effects (86–89). There is increasing focus on the need to evolve strategies for prevention, early identification and treatment of the morbidities in survivors that are related to earlier treatment – the price of cure.

Success in this endeavour would be rewarded by improvement in the health-related quality of life of the survivors, thereby increasing their abilities to achieve personal goals while becoming productive members of society, to the benefit of the nation. Early evidence of the value of this investment has been shown by different groups studying the long-term needs of children with cancer (90–92).

Late effects from initial cancer treatment are most common after intensive cancer therapies such as haematopoietic stem cell transplant, radiation therapy and intensive chemotherapy regimens, for example, acute myeloid leukaemia.

Less intensive, risk-stratified chemotherapy regimens, more commonly used in LMIC, have been shown to carry less long-term risk of mortality (93,94).

It must be recognized that long-term follow-up of childhood cancer survivors is crucial to promote healthy lifestyles and to prevent or detect early diseases related to initial cancer treatment or cancer-predisposing genetic conditions (Figure 19). Childhood cancer survivors who are engaged in survivorship care can achieve better health and educational outcomes than survivors who do not receive care during this time (95).



**Figure 19. Percentage of childhood cancer survivors in need of long-term care**

Source: Institute of Medicine (US) and National Research Council (US) National Cancer Policy Board 2003 (96).



Evidence-based strategies are needed to inform survivorship care requirements in the five domains of survivorship care (Figure 20). Core actions include development and implementation of evidence-based guidelines, adequate multidisciplinary infrastructure, coordinated referral pathways between specialists and primary care providers, and individualized care plans with the scope of aiming to ensure the best quality of life for the children throughout their lifetime (97).

Additionally, survivors should be educated about how to manage their risk of developing specific health conditions as they mature

and can benefit from information on how to maintain a healthy lifestyle after cancer treatment (95). Governmental national cancer plans may be utilized to educate survivors and their families about reducing risky behaviours such as avoidance of smoking and minimizing alcohol intake, maintaining a healthy weight, exercising and consuming a healthy diet. There is evidence to suggest that a subgroup of childhood cancer survivors and parents experience increased psychological distress and other mental health conditions after cancer treatment (98), and may require long-term psychological support.

**Figure 20. Five domains of survivorship care**



Source: WHO 2020 (6).

**Fertility preservation:** While the majority of childhood cancer survivors are able to have children of their own, long-term fertility risks secondary to cancer treatment exist and must be addressed, particularly in the AYA population for whom concern around fertility is more relevant (99). These risks can include inability to achieve or carry a pregnancy to term, but also increased maternal morbidity and preterm birth (100). The fertility risks are also an additional cause of distress for patients going through treatment or experienced after treatment and have led to increasing interest in the field

of fertility preservation. Conversations between providers and young people or children's parents should be started early during treatment. Sperm and oocyte collection are considered standard strategies, others (gonadal tissue biopsy and cryopreservation, pharmacological protection of gonads) are still undergoing data review (101). Continued investments in clinical trials and research are needed, as well as training of health care providers in oncofertility via competency frameworks (102,103).





Better survival means something different to everyone, but as a survivor means, a better quality of life

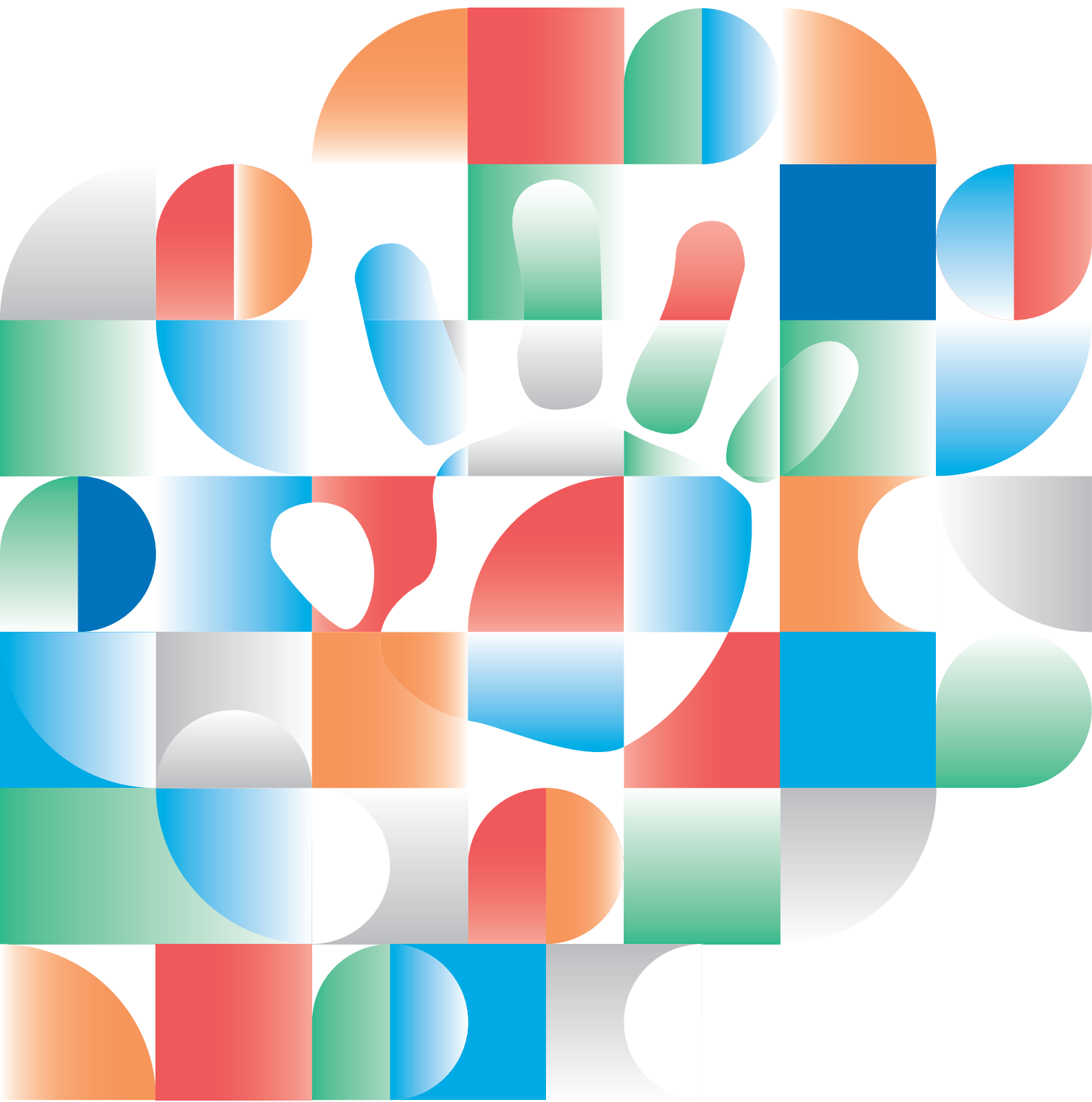
— Emma

Survivor of medulloblastoma

## Section 3.

# CureAll: priority interventions







## 3.1

# PILLAR 1: CENTRES OF EXCELLENCE AND CARE NETWORKS TO INCREASE ACCESS TO QUALITY HEALTH SERVICES

### RATIONALE

**Context:** The continuum of care for children with cancer requires complex combinations of interventions delivered at different levels of service in a coordinated care system: from the community to specialized treatment centres, coupled with efficient transitions between levels of care and informed by established referral and counter-referral networks. Improving capacities and service provision at all levels of care ensures timely diagnosis, appropriate multidisciplinary care for children and adolescents, and the ability to link to care closer to home for shared care and to facilitate adherence to treatment.

#### The core elements of Pillar 1 are:

- effective model of care with referral and counter-referral pathways
- trained multidisciplinary workforce
- facilities with appropriate infrastructure and technologies.

**Models of care:** Effective models of care mean ensuring that services are coordinated at all levels from community to specialized treatment centres and that services are oriented towards providing care closer to home, when possible, in the co-production of health and include health promotion enabling timely diagnosis through disease awareness and treatment care plans (104). Both the capacity and the organization of services impact childhood cancer outcomes. Cancer centres cannot function in isolation and must be linked to the ability to access it through networks of care at all levels of care.

While centralization of services can improve efficiency, it can also exacerbate inequitable access for rural populations or those geographically removed from that centre (6). To balance the need for centralized specialty services in childhood cancer, investments are needed in public health programmes to increase awareness of childhood cancer signs and symptoms at the primary care level, to develop well-defined referral pathways and to strengthen secondary

care services. A child with cancer may require more than 100 health facility encounters throughout the duration of care. Increasing the number of visits at facilities close to home reduce the direct and indirect costs of diagnosis and treatment, through a child- and family-centred approach.

National- or state-level cancer centres able to provide specialized childhood cancer care can also be linked to regional networks to facilitate access to the most complex set of services, promote collaboration in patient care and research, share knowledge and build capacity.

#### Comprehensive care involving multidisciplinary teams:

Multidisciplinary teams are crucial in paediatric oncology and achieving optimal survival requires a sufficiently large and qualified health workforce to deliver key services. Multiple, diverse competencies in childhood cancers are required along the patient pathway for care to be effective.

The elements of the workforce for childhood cancer should be defined through a competency-based framework (59) that promotes optimization of skills and can improve access to and quality of cancer care (105). This should be founded on defined skill mix coupled to accreditation schemes.

The availability of services is proportionally related to workforce capacity, which is a major barrier to be rectified particularly in many LMIC. A deficit in one health discipline can serve as a broad bottleneck resulting in inferior outcomes. For example, a diagnosis of Burkitt lymphoma may require providers to counsel the patient, obtain images, perform image-guided biopsy, offer symptoms control (including pain relief), process the specimen, interpret the findings and communicate the results.

These services may be performed in two or three different facilities and require diverse competencies that are interlinked, requiring close communication.

Management of childhood cancer is multimodal and as such a significant diversity of medical professionals is required, reaching as many as 100 different types of occupations involved. The specific competencies required to care for children with cancer should be evaluated for availability, including often neglected competencies in nursing, nutritional support, psychosocial support, infection prevention and control, and supportive and palliative care (see Section 2.4).

Accreditation of providers and regulation of training allows standardization of provider education and promotes quality of providers, facilities, or both. This has been shown to improve outcomes in cancer care (106).

#### Facilities with appropriate infrastructure and technologies:

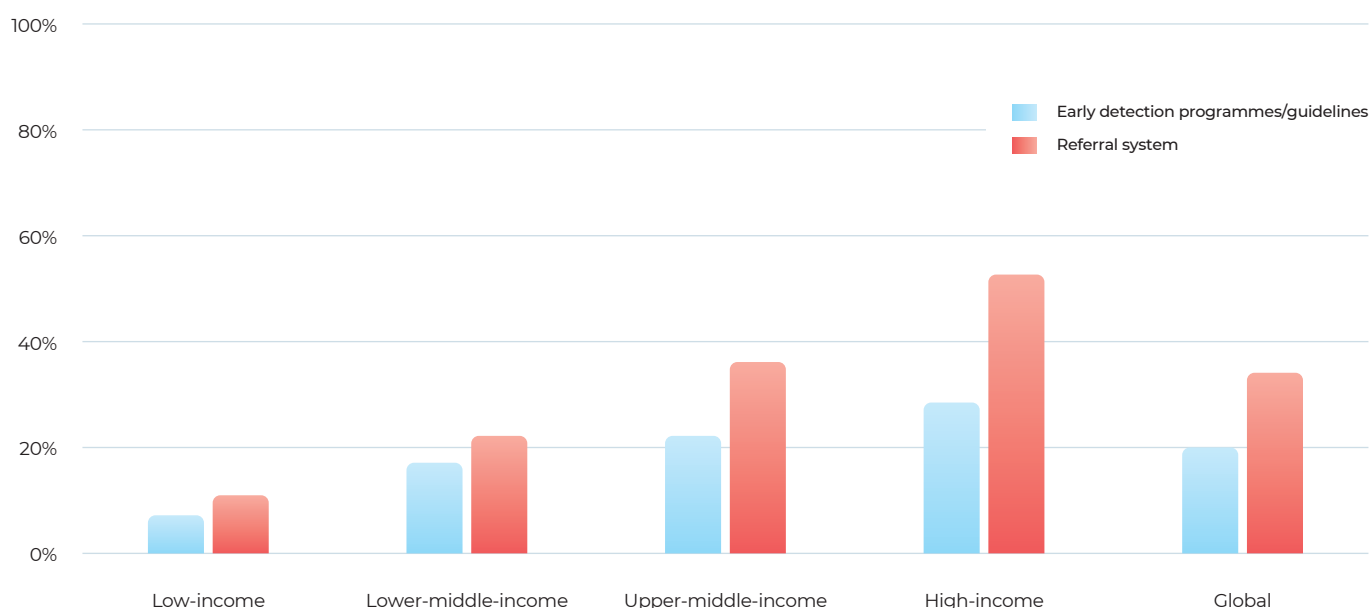
Childhood cancer services are dependent on the availability of functional priority medical devices. The WHO List of Priority Medical Devices for Cancer Management documents 1020 medical devices required to perform 248 clinical interventions for cancer control (9). These include capital equipment as well as single-use equipment, consumables, reagents, accessories and protection devices, and information systems. These devices and technologies support: laboratory medicine, blood bank, pathology (immunostains, cytogenetics, molecular diagnostics), pharmacy, nursing, radiology and radiotherapy suites tooled with anaesthesia equipment, radiotherapy planning and treatment delivery equipment, instrumentation for paediatric surgery, equipment for ophthalmology, computerized information systems, among others.

Children with cancer are often immunocompromised. The separation of the children with cancer into wards or areas within the hospital where specialized services and specific infection prevention and control measures are in place is preferable. As programmes scale-up, more space may be needed for inpatient and outpatient facilities. The infrastructures and technologies available at each level of care are defined to meet certain standards according to the complexity of the services delivered at that level of care.

In select situations, care in national centres or centres outside the country may be required to access specialty diagnostic or treatment services (e.g. stem cell transplantation or intra-arterial chemotherapy for retinoblastoma). This can offer children with select conditions and/or needs the highest likelihood of survival. However, guidelines for such referrals must be established to avoid inequities in access and to ensure these services are affordable and provide appropriate follow-up of patients treated in other centres.

**Current situation:** Capacity to diagnose early and manage childhood cancer cases remains limited in many LMIC. In a recent survey, only 20% of countries globally reported having early detection programmes or guidelines to strengthen early diagnosis of childhood cancer symptoms at the primary care level (Figure 21). A clearly defined referral system from primary care to secondary and tertiary care for suspected childhood cancer cases was more broadly available, but still exists in a third of countries (34).

**Figure 21. Percentage of countries with early detection programmes/guidelines and referral system for suspected childhood cancer cases, by World Bank income group, 2019**

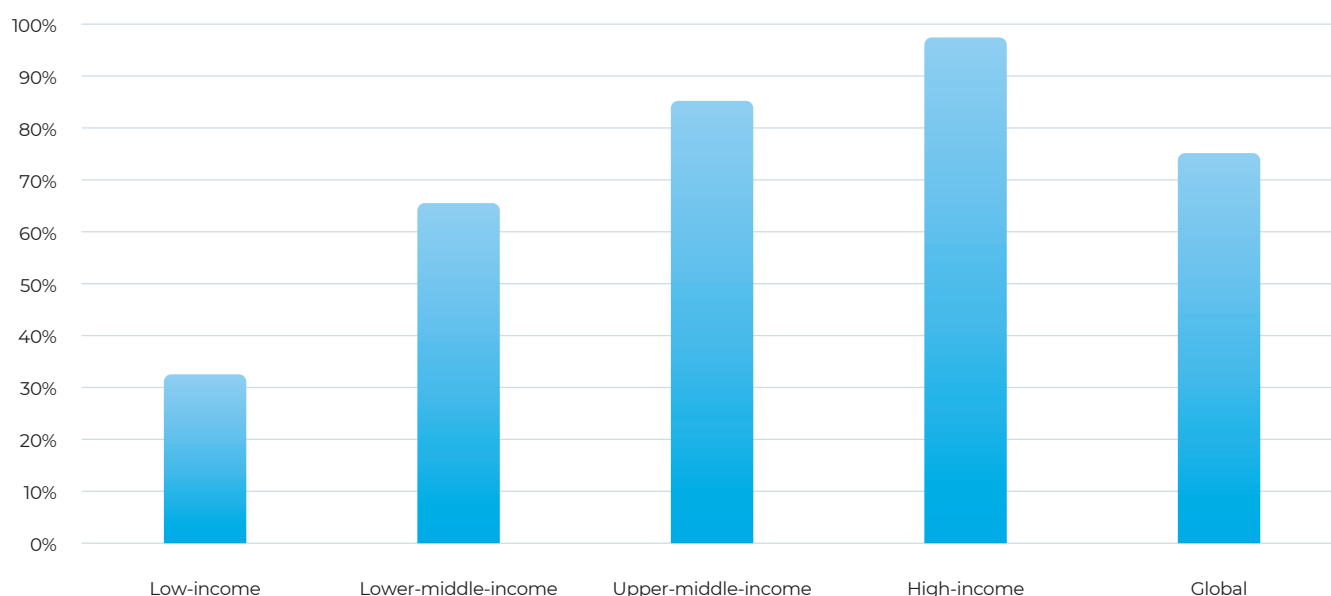


Source: WHO 2020 (34).

While scope and scale of cancer centres may vary by country, they are generally defined as institutions specializing in cancer diagnosis and treatment (107). In 2019, 32% of LIC reported that their cancer centres or cancer departments within tertiary institutions in the public health sector were generally accessible, reaching over 50% of the patients in need (Figure 22) (34). These data, however, encompass both adults and children, and many of these centres are not likely to provide childhood services. The prevalence of availability for key cancer services, such as pathology,

surgery, chemotherapy and radiotherapy, were also limited in LMIC and found to increase with income group (see Section 1.2.3). A study conducted in 35 European countries revealed that only half reported sufficient childhood cancer centre capacity relating to the availability of equipment and facility infrastructure, contributing to significant inequalities in access to care and outcomes for children with cancer (108).

**Figure 22. Percentage of countries with tertiary level cancer centres or departments, by World Bank income group, 2019**



Source: WHO 2020 (34).

Inadequate awareness of childhood cancer, coupled with poor referral networks or difficulty accessing tertiary centres, lead to delays in diagnosis. Since cancers are then diagnosed at a more advanced stage of disease, the burden of treatment increases. Patients can also present with more complications or co-morbidities such as malnutrition. This contributes to increased treatment toxicity, leading to a higher risk of toxic deaths and treatment abandonment (67).

Lack of appropriate workforce competencies or infrastructure within cancer centres leads to inaccurate diagnosis, which can also result in the inappropriate use of intensive therapies. A study from Mexico, for example, showed that the number of providers and hospital beds for childhood cancer correlated with outcomes (109). Investing in additional capacity in childhood cancer care and addressing causes of treatment failure have been proven to be efficacious and improve survival (110).

In relation to the delivery of nursing care, large disparities exist worldwide, illustrated by a high nurse–patient ratio, inadequate nursing practice environment, insufficient nursing education and less inclusion of nursing staff in multidisciplinary care in LIC and LMIC (101). A study from Ghana reported nursing shortages, excessive workload, lack of support from hospitals and lack of confidence in their training. These factors contribute to poor quality of care and difficulty to deliver patient-centered care (112,113). Other workforce competencies crucial to childhood cancer care also suffer from these inequities. For example, the availability of dieticians in paediatric oncology units is scarce, as shown by a study conducted in childhood cancer units in 31 African countries. Less than half of those centres had dedicated professionals for nutritional assessment and support, and parenteral and enteral nutritional support was available in only 42% and 52% of the units, respectively. This highlights the need for a trained workforce in supportive care, but also the need to source appropriate supplies.

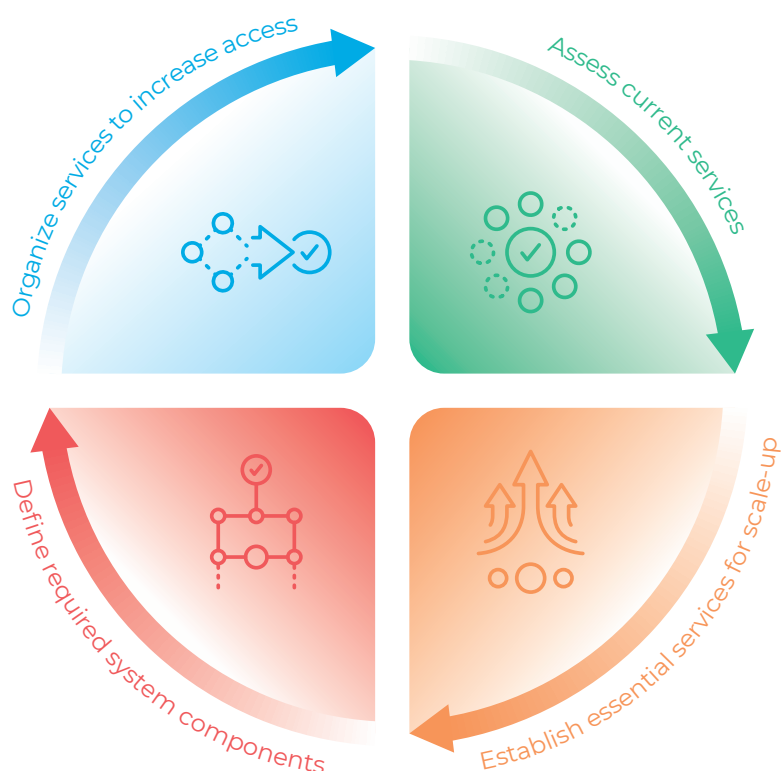


## WHAT TO DO

**Foundation:** Improving access to childhood cancer services begins by establishing which interventions should be provided and at which service level, according to a priority setting exercise (Figure 23). Each intervention has accompanying health system requirements, including the necessary trained health workforce and the associated priority medical devices that must be defined.

Comprehensive services must link diagnosis (e.g. pathology, radiology) to treatment (e.g. systemic therapy, surgery, radiation therapy, nuclear medicine) and to essential supportive services for childhood cancer (Figure 24) (see Section 2.4).

**Figure 23. Steps to increase system capacity in centres of excellence and care networks**



**Figure 24. Sample essential functions and linked competencies**

	Early diagnosis and referral	Diagnosis	Treatment	Supportive care, palliative care	Survivorship care
Sample occupation	Primary care medical staff, general practitioner, general paediatrician	Radiologist	Paediatric oncology nurse	Psychologist	Childhood cancer late effects specialist or trained physician
Sample role	<p>Responsible for the detection of early signs and symptoms of childhood cancer</p> <p>Initial clinical assessment</p> <p>Management of symptoms and complications</p> <p>Referral to a secondary or tertiary centre</p>	<p>Responsible for the medical aspects of procedures including the justification of studies</p> <p>Interpretation of diagnostic imaging (ultrasound, X-ray, CT, MRI)</p> <p>Supervision and interpretation</p> <p>Performance of image-guided biopsy techniques (with additional training)</p>	<p>Counselling and educating families</p> <p>Safe administration of chemotherapy and early detection of toxicity</p> <p>Management of simple toxicity</p> <p>Management of vascular access devices</p>	<p>Psychological assessment and treatment for patient and family</p> <p>Bereavement support</p>	<p>Surveillance for long-term effects of therapy and recurrence of cancer or development of secondary malignancies</p> <p>Liaison with other providers as required</p>

Service capacity and need should also be monitored carefully over time. Needs may rapidly change as either the influx of new patients (particularly in LMICs as those previously undiagnosed or misdiagnosed enter the system) or as treatment complexity increases.

### Priority action: Develop models of care that prioritize primary care and robust referral mechanisms

A robust model of care can improve access to timely, quality care. Primary care serves an important function in reducing delays as most children with cancer first seek attention at facilities close to their homes. Training primary health care teams on the signs and symptoms of childhood cancer leads to early diagnosis (Table 3).

**Table 3. Examples of symptoms and signs of common childhood cancers**

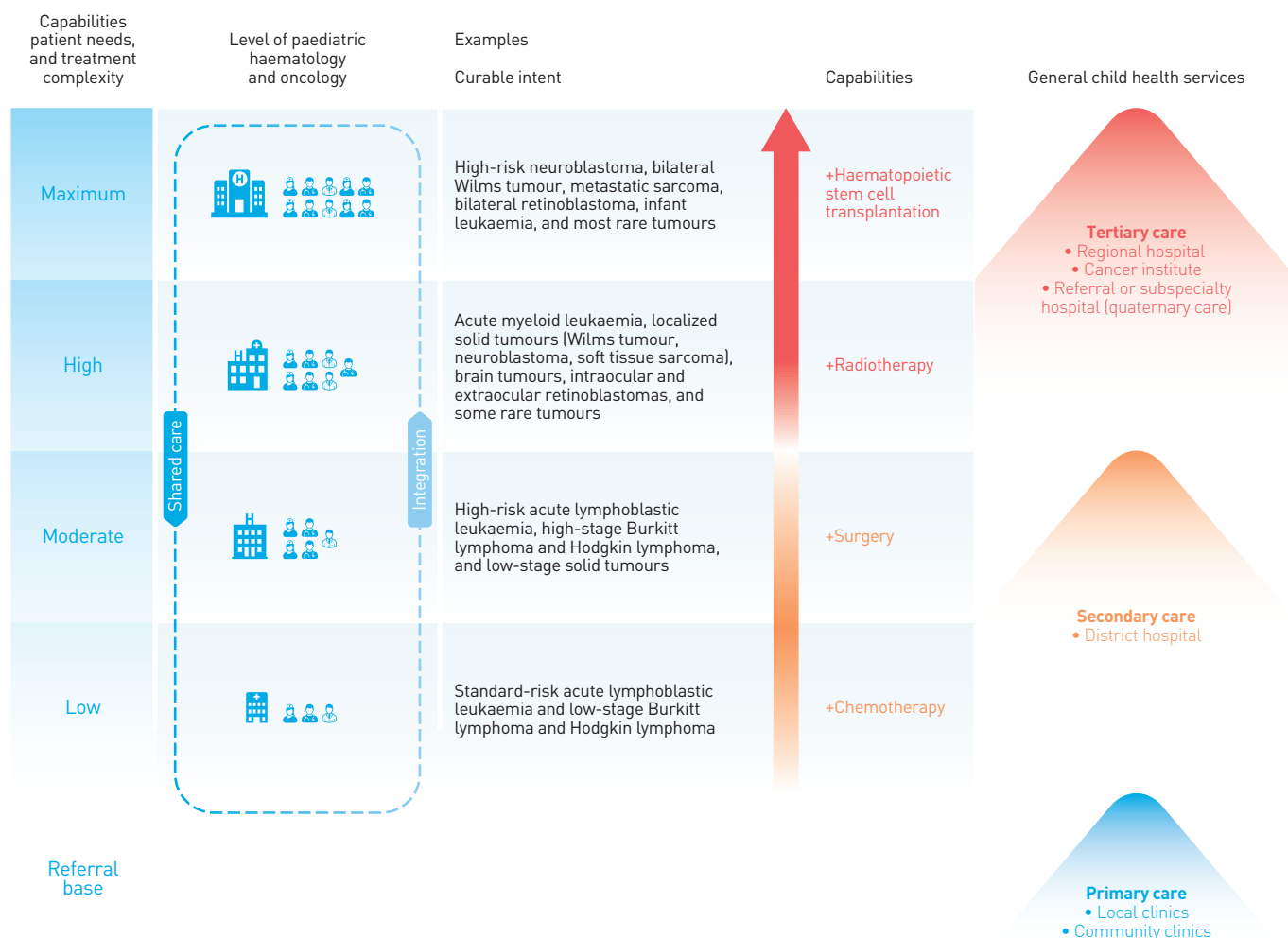
Type of cancer	Symptom	Sign
Leukaemia	Fatigue, loss of appetite, fever, bone pain, bruising or bleeding, symptoms of anaemia	Fever, pallor, petechiae, ecchymoses, signs of bleeding, hepatosplenomegaly, lymphadenopathy, infiltration of other organs (CNS, testicles), signs of anaemia
Lymphoma	Fatigue, loss of appetite, fever, night sweats, symptoms of anaemia, presence of a mass with associated symptoms (difficulty breathing, abdominal distension, abdominal pain)	Lymphadenopathy, mediastinal mass with or without pleural effusion, tachypnoea, dyspnoea, difficulty breathing, superior vena cava compression
CNS tumours	Headache, nausea and vomiting (symptoms of raised intracranial pressure); focal motor, sensory, facial, visual symptoms; seizures, behavioural/schooling issues Infants: developmental regression	Papilledema if raised intracranial pressure; Focal neurological signs; ataxia Infants: increase in head circumference
Abdominal tumours (Wilms, neuroblastoma, rhabdomyosarcoma, germ cell tumour)	Abdominal distension, with or without pain; With or without fatigue, weight loss, fever, symptoms of anaemia; +/- haematuria; sometimes asymptomatic	Palpable mass Symptoms of anaemia +/- Hypertension +/- Lymphadenopathies
Musculo-skeletal tumours	Presence of a mass, pain, limping without a history of trauma	Palpable mass, loss of function Can cause compression of surrounding structures
Retinoblastoma	Loss of vision and pain	Leukocoria (white-eye), strabismus, mass/proptosis (advanced stages), enlarged eye

Source: Pan American Health Organization 2014 (114).

Efficient referral mechanisms to designated centres of excellence can further reduce delays in care by enabling timely pathologic diagnosis and treatment. Coordinated service delivery is thus critical

to linking services between primary- and secondary-level facilities and the cancer centre through care pathways and referral criteria, ultimately achieving equity, effectiveness and efficiency (Figure 25).

**Figure 25. Levels of cancer care**



Source: Atun 2020 (33).

When scaling up, it is fundamental to balance the competing priorities of quality and access. Minimum capacity and requirements for facilities to deliver safe care at each level must be defined. Cancer units may have the capacity to offer common diagnostic and treatment services, however, complex childhood cancer care requires multidisciplinary capacity available in national cancer referral centres (with comprehensive services, including oncology, surgery, radiotherapy, pathology, radiology, psychosocial support, nutrition and rehabilitation services). Palliative care is one essential service in all cancer programmes that should be accessible at all levels of care, from community health through cancer centres (Figure 26).

National cancer centres should be well connected with a network of cancer centres or cancer units. Active treatment must be coordinated between facilities, levels of care and disciplines, with routine reporting. The cost-effectiveness of treating cancer in centres with higher capabilities is established through known economies of scale (28,175). In addition, formation of national childhood cancer professional networks should be encouraged to promote collaboration and collegialism between cancer centres.

**Figure 26. Sample distribution of cancer management services by hospital capacity**

### Tertiary care level

#### Complex diagnosis and Staging

CT, MRI, PET, cytogenetics and molecular genetics

#### Specialized treatment

Specialized surgery, radiotherapy, all chemotherapy

#### Palliative care

(initial control of moderate to severe symptoms)

#### Survivorship care

### Secondary care level

#### Routine diagnosis

Core biopsy, histopathology, ultrasound, X-ray, CT

#### Standard treatment

Limited simple chemotherapy, less complex cancer surgery

#### Palliative care

#### Survivorship care

### Primary care level

Health promotion

Education and training of community health workers and caregivers

HPV vaccination

Retinoblastoma screening

Education on early warning signs for childhood cancer

#### Palliative care

(ongoing care for patients with well-controlled symptoms)

#### Survivorship care

Source: WHO 2020 (56).

### Priority action: Define required competencies and strengthen training of personnel at all levels of care

Public sector strategic direction in the cancer workforce is fundamental to sustain cancer services, design policies addressing local needs and build on international experience.

Workforce planning should be preceded by a needs assessment to guide the development of competency-based training programmes and alignment with graduate and nursing school curricula (116). Labour market forces should be analysed to understand the supply and demand of a health workforce with the following aims: (i) to increase the number of training positions to a more appropriate number for the demand; (ii) to optimize the skill mix of providers; (iii) to address and prevent attrition rates; (iv) to establish professional development pathways and continuity of education; and (v) to develop recognized specialty training programmes and maintain accreditation.

International collaboration to support in-country or regional training results in very high retention rates and builds local expertise providing high-quality care adapted to context. Team-based and practical learning have a particular role in in-service training and should be prioritized over imparting theoretical knowledge. Focus should be on continuous professional development through organized programmes that must be adhered to in order to maintain accreditation or registration and linked to outcomes. Early evidence has shown that tele-medicine may be effective when scaling up capacity and that tele-mentoring is effective and feasible (117,118).

Workforce capacity must be linked to defined sets of services and standards of care (Box 7, Box 8). Nursing competencies are important for the dialogue on quality of care and deserve particular attention. Accreditation of staff should be verified regularly based on ongoing competencies and completion of continuous professional development.



## Box 7. Sample services/competencies and occupations

**Nursing:** Nursing skills in childhood cancer care adhere to higher levels of standards and often require formalized training (119). Accordingly, avoidance of rotating to other general paediatric services can enable increased competencies. Nurses may benefit from protected time for continuous professional development and should be involved in multidisciplinary team discussions when appropriate.

**Physician:** Advanced competencies are also required for medical staff caring for children with cancer, including expertise in oncology and paediatrics. Diverse medical specialties with a focus in paediatrics are needed and include, for example, anatomical pathology, radiology, surgery, radiation oncology, paediatric oncology and broader specialties required for supportive services (e.g. intensive care). Subspecialty medical staff such as paediatric medical subspecialties in cardiology, gastro-enterology, infectious diseases and surgical subspecialists (e.g. orthopaedic surgeon, otolaryngology, neurosurgeon) may be required for consultations to deliver advanced services in comprehensive cancer centres.

**Nutrition:** Competencies related to the prompt evaluation of nutritional status and implementation of nutritional interventions are needed to improve outcomes and to support growth and development. In addition to providers such as trained dietitians, medical and nursing staff training can support delivery of nutrition-related interventions.

**Psycho-oncology, social work:** Psycho-oncology professionals and social workers are needed to provide support to families and patients during and after treatment, improving adherence and helping cope with the burden of treatment.

**Infection prevention and control:** Medical staff need to ensure appropriate treatment and isolation of patients with infectious diseases and antibiotic stewardship.

**Pharmacy:** Designated staff should be trained in chemotherapy prescription, sterile preparation and common interactions to ensure safety of systemic therapy.

**Radiation oncology:** A diversity of competencies is required for the safe delivery of radiation oncology. Common occupations required for the delivery of safe radiotherapy may include radiation oncologists, medical physicists and radiation technologists who received training in the specific competencies required to deliver radiotherapy to children with cancer (120,121), as well as anaesthetists for the delivery of general anaesthesia for young children.



## Priority action: Ensure infrastructure and technologies available at each level of care

The selection of devices and equipment should be based on agreed priority interventions and an associated workforce and only performed after an appropriate needs assessment of the facility and the level of care it delivers. It is all too common that technologies are purchased without considering system readiness to deliver the associated service or maintain the device. This results in non-functional or inappropriately used equipment. For example, the purchase and installation of MRI machines should be reserved for specialty cancer centres where there is sufficient volume of cases with indications for such imaging and where the expertise is available to interpret images and personnel are available to maintain the technology. Conversely, ultrasound, which has broader diagnostic value, may be available at lower levels of care.

Advanced and more complex oncological services, such as stem cell transplantation (SCT) and other cell therapies, intra-arterial administration of chemotherapy (such as for retinoblastoma), intensive chemotherapy regimens (such as high-risk acute myeloid leukaemia) or complex surgery (such as orthopaedic or hepatobiliary surgery) should be developed through organized planning and coordinated service structure. At the country level, these services should only be introduced after more basic quality capacities are available and only when an appropriate readiness evaluation has

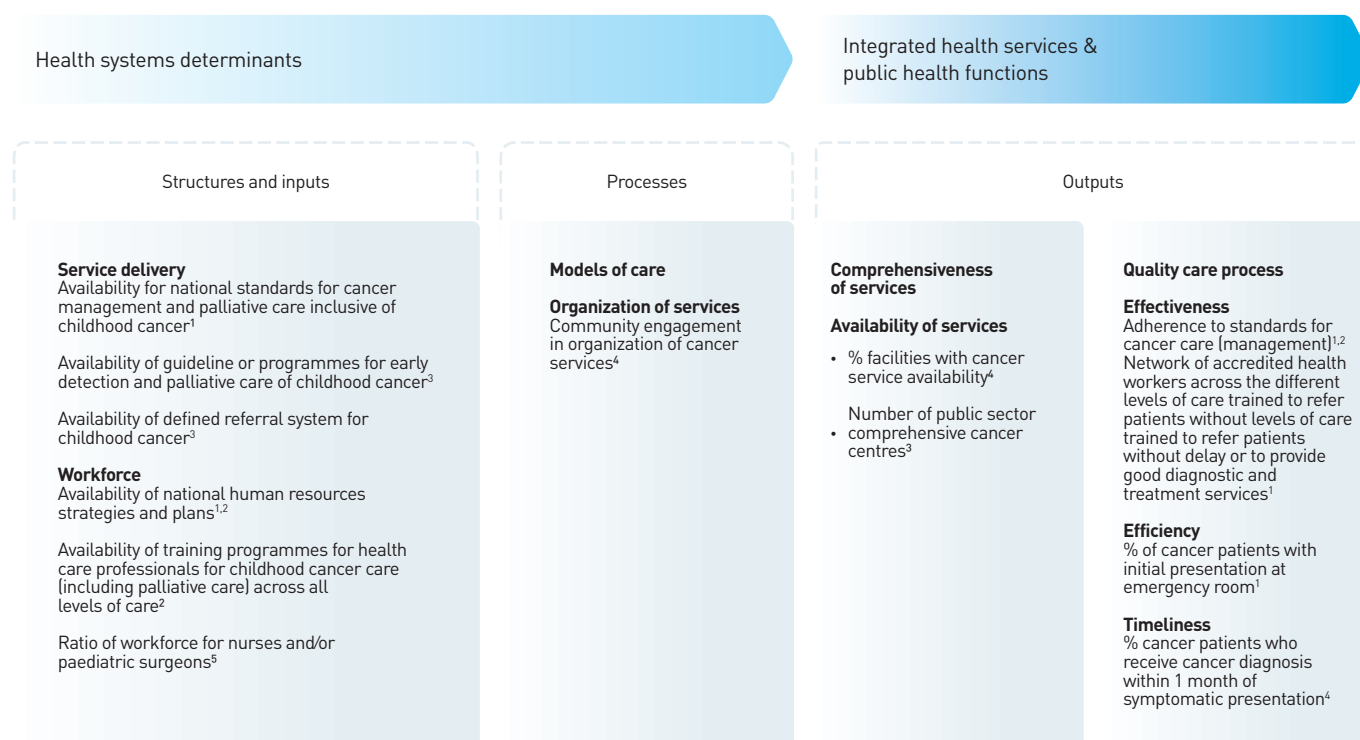
been performed at a specialized centre, including preparedness of a sufficient trained workforce. This is the model of progressive realization towards UHC (see Section 3.2) and allows for investments in higher impact, lower cost clinical services (see Section 1.5). When a facility is planning to increase the complexity of its services, it must be linked to national cancer control planning to ensure accessibility to all populations and sustainability.

Standards of care and safety for the technology should also be established. For example, pathology specimen (such as diagnostic material, for example, immunohistochemistry, molecular biology and cytogenetics) transportation and reception should be timely and protocolized linked to the National Lists of in vitro Essential Diagnostics (EDL) (122). Standards should also be developed for diagnostic imaging to reduce potential harm to children from ionizing radiation (123), as well as national quality and accreditation standards in radiation oncology with quality and safety requirements. These standards are critical for safe delivery of technologies and to maximize effective clinical use (56).

## SAMPLE METRICS

Figure 27 outlines sample indicators for quality childhood cancer care services.

**Figure 27. Sample metrics quality childhood cancer care services**



Sources: 1. WHO 2006 (124); 2. WHO Regional Office for the Eastern Mediterranean 2017 (125); 3. WHO 2021 (126); 4. WHO 2014 (127); 5. Vasquez et al. 2021 (52).

Brian Walusimbi, Bless a Child Foundation, Uganda



## CASE STUDY

### **Box 8. Ghana: Childhood cancer workforce priorities and capacity-building**

*In November 2019, the second national stakeholder workshop took place in Accra, Ghana, with the participation of members of the Ministry of Health, WHO African Regional Office, WHO Country Office, WHO headquarters, Ghanaian universities, major hospitals treating children with cancer, international partners such as World Child Cancer, the International Society for Paediatric Oncology, St. Jude Children's Research Hospital and local nongovernmental organizations and parent groups. A technical session focused on discussing a health systems-based approach to childhood cancer that included addressing the need of a workforce and coordinated service delivery as part of a response linked to the National Cancer Plan. The workshop concluded with four defined priorities, two of which were to accelerate training of a multidisciplinary workforce and to improve care pathways to facilitate early diagnosis. Focusing on the need to develop a multidisciplinary competent workforce and implementation of priority interventions, Ghanaian professionals have focused on capacity-building and nursing education and training through the School of Nursing in Ghana, collaborating with a global network with support from World Child Cancer United Kingdom, among others.*



## 3.2

# PILLAR 2: UNIVERSAL HEALTH COVERAGE (UHC) AND INTEGRATION OF CHILDHOOD CANCER

### RATIONALE

**Context:** UHC is defined as ensuring that all people have access to needed and quality health services, without suffering financial hardship. UHC is a political commitment made by all governments as part of the United Nations 2030 Agenda for Sustainable Development (target 3.8) and a core mandate and priority for WHO. UHC has two components:

- Access to quality essential health care services, including prevention, promotion, treatment, rehabilitation and palliation that comprises access to safe, effective, quality and affordable essential medicines and vaccines.
- Protection from financial risk associated with seeking and receiving care.

To date, insufficient progress has been made in childhood cancer. Access to quality services remains low in many LMIC, and many families rely on out-of-pocket payments as a common form of financing services (128), including in childhood cancer.

The lack of secure financing mechanisms for childhood cancer services leads to a series of devastating consequences, including abandonment, higher mortality and relapse in children without access to social security or health insurance and an increased risk of financial catastrophe for families (Table 4) (129). Downstream, families are pushed into poverty, disrupting social stability, employment opportunities and the health of siblings and other family members (130).

**Table 4. Consequences of lack of secure financing mechanisms**

Delayed diagnoses due to a lag or avoidance in seeking care, which in turn can lead to complications secondary to cancers left untreated, including severe infection, malnutrition and cancer-specific complications, some of which can be long term.

Advanced-stage cancers at presentation, secondary to delays or avoidance in seeking care, resulting in the need for more intensive treatments that carry higher rates of toxicity, treatment-related morbidity and mortality, progressive disease and relapse (127).

Higher rates of treatment abandonment secondary to financial catastrophe, loss of employment or habitation, debt or destitution for families attempting to fund their child's treatment (58,128).

Inadequate supportive care leading to risk of death or increased suffering due to infection, malnutrition, inaccessibility of safe blood products, inadequate psychosocial support.

Difficult access to quality palliative care services due to inaccessible services, resulting in painful, distressing and unsupported course of treatment, end-of-life and death.

A prioritized set of core interventions included in a benefit package as part of UHC can reduce financial hardship and is most effective when it includes supportive services. The inclusion of palliative care services in essential packages is an equity imperative, in order to alleviate pain and other types of suffering for children with life-threatening illnesses (87). This aligns strongly with the **CureAll** target to improve survival and to relieve suffering for all children.

Palliative care is cost effective and affordable (131) and can avoid unnecessary hospitalizations and expenditures. Improving access to palliative care services, including quality treatment of pain, can alleviate physical, psychosocial and spiritual suffering, improving quality of life for children and their families and ensuring basic children's needs are met. Service needs are likely to increase as



paediatric oncology services scale up in countries and more children and their families seek care services and are particularly vulnerable to financial toxicity.

**Current situation:** Unacceptable inequalities exist worldwide in access to quality cancer care and financial protection. These inequalities have been conveyed in recent efforts to report effective coverage of essential services, using outcomes from acute lymphoblastic leukaemia as a tracer because of these established inequalities (42).

Even in settings where childhood cancer services exist as a result of facility-level collaboration and/or support from nongovernmental organizations or foundations, a substantial proportion of the overall population may not have access because of a failure to include childhood cancer in broader financing envelopes, thus increasing inequity in access to care (33,132).

The global socioeconomic impact of childhood cancer treatment on families has been well described and encompasses the direct cost of medical care, but also indirect costs such as loss of employment or productivity, and out-of-pocket expenses due to child care, travel, accommodation or food. Studies report disruptions to parental employment and income during childhood cancer treatment, particularly for mothers (see Section 1.2.4). In one study, as many as 30–50% of families had one parent needing to stop working in order to care for their child during treatment (133). This phenomenon is seen in countries of all income levels, but it is more pronounced in families of low socioeconomic background and single parent families as well as in LMIC, pushing families into debt and leading to interruptions in treatment (35,134). Hardship tends to occur just after diagnosis and at the start of treatment, when the financial and social impact of a new diagnosis is greatest, but can perdure into early survivorship (135).

The current level of coverage for children with cancer and funding allocated for children in national cancer control plans is largely unknown due to lack of reliable data and lack of inclusion of cancer and childhood cancer in national health accounts. As countries define their benefit packages and make such data available, more data can be acquired regarding childhood cancer. Additionally, some countries have recently expanded their essential services and/or introduced legislative commitments to include childhood cancer in benefit packages (Box 9).



### Box 9. Country examples of expanding health care coverage that includes children (136)

- In Mexico, the Fund for Protection against Catastrophic Expenditure of the Seguro Popular has been allocating a budget since 2006 for childhood cancer services for families with no health coverage, starting with acute lymphoblastic leukaemia and expanding to all cancers in 2008, covering an estimated 50% of children with cancer by 2009 (137). While this represents major progress, funding schemes need to be consistent and sustained in order to prevent financial toxicity, and coverage must be equally distributed throughout the country (138).
- In the Philippines, where UHC has recently been prioritized, insurance coverage was expanded to cover the costs of diagnosis and treatment of childhood acute lymphoblastic leukaemia through the Z Benefits Program, prioritizing patients with the lowest socioeconomic background. This program is operated in conjunction with the ALL Medicine Access Program to provide free chemotherapeutic drugs to acute lymphoblastic leukaemia patients, although the costs associated with managing complications of treatment are generally not covered by these programs.
- China initially launched a health insurance initiative in the early 2000s that included catastrophic diseases inclusive of select childhood cancers. The degree of coverage and cost sharing depends on the counties, and scale-up has been impacted by the progressive cost of cancer services (139). Cancer remains a political priority area as expressed in the Chinese government's Healthy China Action Plan.
- In Thailand, a universal coverage scheme that includes childhood cancer was introduced in 2002 and has been financed with a mix of resources, including general taxes, social health insurance contributions, private insurance premiums and a relatively low out-of-pocket payment fraction. Utilization of health services including for cancer has increased, specifically for vulnerable populations, and has been shown to improve earlier diagnosis of cancer (51,139).

Regarding coverage of palliative care services, data on service availability and inclusion in UHC benefit packages are even more scarce. Current assessments are that the vast minority of children have access to palliative care with data from select countries in the WHO African Region, estimating that less than 5% have access (140,141).

In 2019, national service availability statistics indicated that less than 20% of LIC and LMIC reported palliative care being generally available in a primary care or community- and home-based setting for all ages, reaching only 50% of patients in need. While the palliative care availability in HIC was considerably higher than that of lower-income groups, global availability remained low at 39% and 40% for primary care and community- or home-based care, respectively (34).

## WHAT TO DO

Investing in health leads to long-term health and economic benefits for individuals and societies, including a reduction in mortality rates leading to economic growth, social cohesion and prosperity and increased productivity (see Section 1.5). The strategy of progressive realization, as described by the WHO Consultative Group on Equity and Universal Health Coverage, is relevant to the scale-up of childhood cancer services as part of UHC (Table 5) (127). There is no “one size fits all” and while the overall principles are applicable to all countries, recommendations need to be tailored for each country and its specific needs.

**Table 5. Three-part strategy for progressive realization of UHC**

Categorize services into priority classes, according to cost-effectiveness, priority to the worse-off and financial risk protection.
Expand coverage for high-priority services to everyone. Eliminate out-of-pocket payments while increasing mandatory progressive prepayment with pooling of funds.
Ensure that disadvantaged people are not left behind (including low-income groups and rural populations).

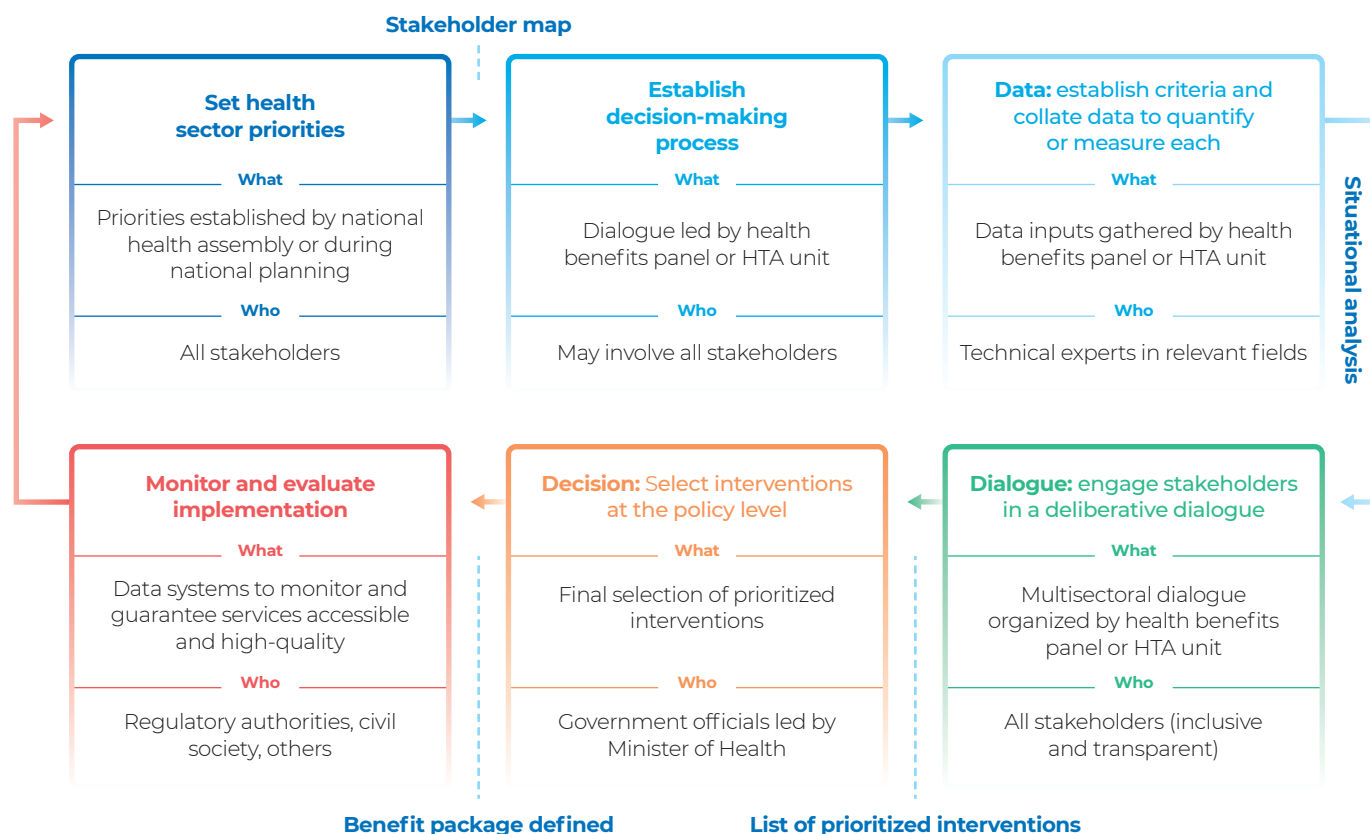
Source: WHO 2014 (127).

Countries’ coverage of care should be progressively expanded to defined essential services for all children with cancer. This process will lead to a reduction in out-of-pocket expenditure on medicines, tests and procedures and also promote access to required multidisciplinary services and providers, such as blood bank services, radiation oncology, surgery, psychosocial support and palliative care. A stepwise process is needed, beginning with a priority setting exercise, and gradually expanding the benefit packages to cover more services and cost-effective interventions as capabilities increase and health systems develop. The process should include establishing priorities, a decision-making process and collecting data, engaging in multisectoral dialogue, and making decisions and monitoring implementation of these defined financed services and programmes (Figure 28).

Indirect costs, such as transportation and housing and/or lost wages for families, may still constitute a particular threat to completing childhood cancer treatment and require innovative responses to reduce the financial burden on families (142). Select examples of support mechanisms to reduce indirect costs include government income supplementation or financial support to offset lost employment time while caring for a child as well as funding for child care for families with several children where parents are unable to care for other children (143).



**Figure 28. Priority setting process for the development of a national benefit package through deliberative consultations**



HTA: health technology assessment  
Source: WHO 2020 (6).

## Foundation: Define priority childhood cancer interventions

The first step in the formulation of a defined benefit package inclusive of childhood cancer is to set health sector priorities inclusive of childhood cancer (Figure 28). A set of prioritized interventions for childhood cancer should be included according to the health system context, feasibility and fiscal space. The subsequent deliberative process would evaluate the data to quantify interventions and costs as well as dialogue with key stakeholders and decision-makers to determine the final selection of interventions.

High-priority interventions and essential services can be defined using existing guidance such as the WHO Model List of Essential Medicines (EML) (144), WHO Model List of Essential in vitro Diagnostics (EDL) (145) and WHO List of Priority Medical Devices for Cancer Management (9), while ensuring that they are well aligned with clinical guidelines and referral services (see Section 1.5).

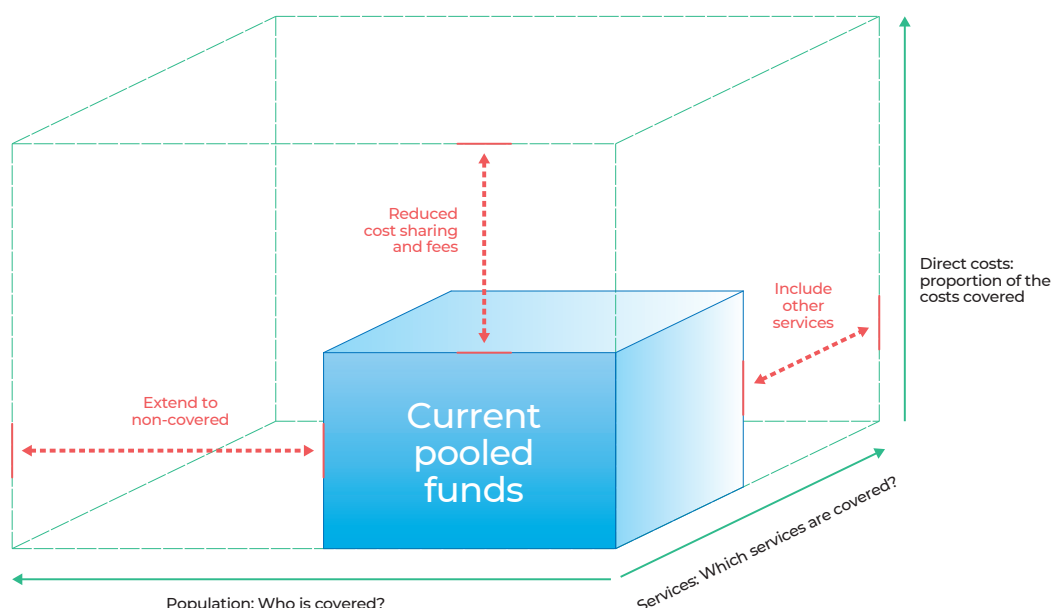
Interventions can either consider all childhood cancers or can begin by focusing on a subset prior to scaling-up to all cancers as has been done successfully in some settings (139,146). Services included should cover the full patient pathway from diagnostics, including pathology

and radiology, to multimodality therapy and supportive and/or palliative care. It is particularly important to include palliative care in a core package of services that is inclusive of the necessary health products and formulations. Other interventions to be included are population-based cancer registries. These allow to determine the needs, monitor the progress and evaluate the efficacy of financial investments.

## Priority action: Expand coverage of high-priority interventions for all

When expanding childhood cancer services to be included in UHC, countries must consider the three dimensions of UHC as well as the service delivery model for defined essential services (Figure 29) (127). Choices need to be made on: (i) which critical services or priority interventions to scale up first; (ii) how to progressively cover the population with the aim of covering all children for the defined priority interventions and before scaling-up to include new services; and (iii) how to maximize the proportion of total costs by government funds and reducing out-of-pocket expenditure.

**Figure 29. Three dimensions of UHC**



Source: WHO 2010 (147).

It is important and preferable that a basic set of essential services is made available to a full population prior to expanding to add new services. This is the principle of progressive realization and the most efficient and equitable way to achieve UHC (127) and to improve populations' outcomes (148,149). The importance of promoting equity is balanced against the rapid pace of innovation in cancer and the capacity of cancer centres to expand complexity of services available to a limited sub-segment of the population. Nonetheless, coverage must include whole populations and not be limited to targeted groups, with priority consideration given to groups that are already marginalized such as those of low socioeconomic status or minority populations.

#### **Priority action: Increase the number and complexity of services**

As the capabilities of UHC grow, additional and more complex childhood cancer services can be integrated into the health care system.

Caution should be used to expand the complexity of services only in centres that have successfully implemented more basic existing services with high quality. National cancer centres may be the first to scale up the number and complexity of services, paired with

the establishment of strong referral networks and the scale-up of workforce (see Section 3.1). Introducing more advanced therapies should only be done after confirmation of broader health system readiness, including the necessary supportive care services (see Section 3.3).

Increasing complexity of services should consider needs along the cancer care pathway from diagnosis to survivorship care and not focus exclusively on treatment-related technologies. This may include, for example, increased investment in early diagnosis through development of provider or parent education material or strengthening capacity in information systems (150). A balance of integrating disease-specific approaches (vertical) with health system (horizontal) interventions may be used in what is known as a "diagonal" approach to inclusion of childhood cancer in UHC. For example, improving education and training of childhood cancer among primary care providers can help strengthen early diagnosis activities across different programmes and link to specialized treatment centres. This strategy has been adopted for other chronic conditions such as breast cancer coverage in Mexico (151), allowing a more comprehensive approach across multiple diseases to deliver early diagnosis, palliative care and survivorship.

## Priority action: Commit a budget for the inclusion of essential childhood cancer interventions into benefit packages

For the defined priority interventions included in benefit packages, the goal is to avoid any out-of-pocket costs for families of children with cancer, and to advance pooling of funds with mandatory prepayments, thus reducing or eliminating financial risk (Box 10).

A sustainable financing strategy must be defined, carefully evaluating possible sources of funding within governmental fiscal capacity to reduce reliance on out-of-pocket payments and increase reliance on prepayment. This can be done by defining a government budget to be allocated to health, apportioning available health resources more effectively and efficiently, strengthening tax administration to generate revenue, reprioritizing health within the government budget if necessary and creating innovative financing mechanisms.

It is important to recognize that domestic resources should be utilized as the foundation of any financing strategy. Public funding, for example, derived from population taxation, may be insufficient to cover costs for even a limited number of childhood cancer essential interventions, particularly in LIC and other settings where current services are paid out-of-pocket. In this case, external and

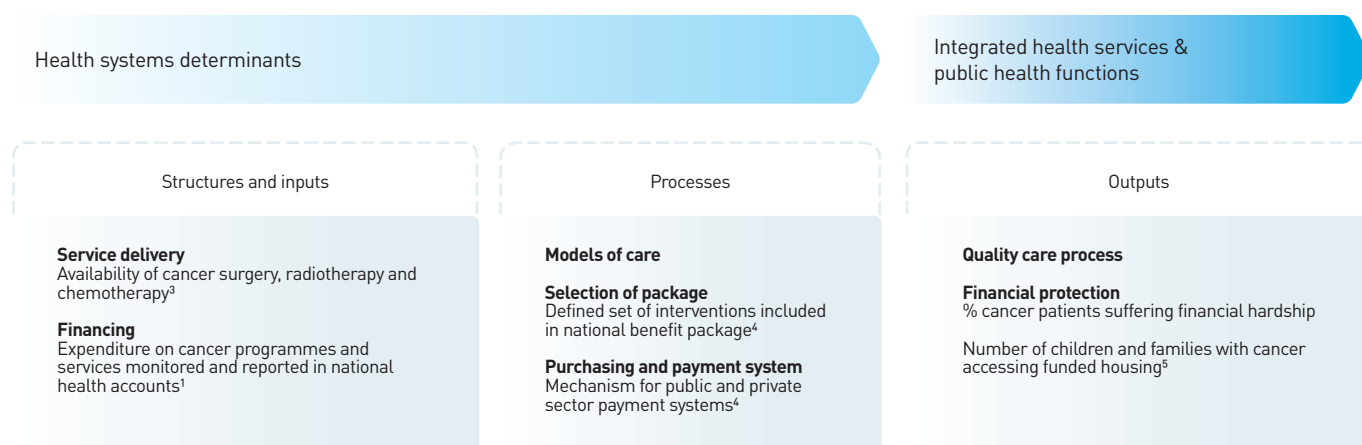
philanthropic funding may be utilized and incorporated into public funding mechanisms, though not replacing it, to avoid unsustainable financing models or inequities in access to care. International funding mechanisms can be used as a catalyst, demonstrating the ability to scale up capacity and thus stimulating the use of domestic resources, with a plan to transition to government resources. External funding alone is neither effective nor sustainable (4,152).

All financing instruments (i.e. mixed models) should be explored and utilized when appropriate. Partnerships can be developed between stakeholders to increase financing opportunities such as governments, private sector, civil society, foundations, philanthropic organizations, external funders and other external organizations (33).

## SAMPLE METRICS

Figure 30 outlines sample indicators relating to the integration of childhood cancer care into UHC.

**Figure 30. Metrics for integrating childhood cancer care into UHC**



Sources: 1. WHO 2006 (124); 3. WHO 2021 (126); 4. WHO 2014 (127); 5. Vasquez et al. 2021 (52).



## CASE STUDY

### Box 10. Peru and the Philippines: Childhood cancer care legislation integrated in UHC

**Peru:** On 2 September 2020, Peru's President and the Peruvian Parliament issued the Childhood Cancer Law, recognizing childhood cancer as a public health priority. The law has three main objectives: UHC for early diagnoses and cancer-related treatment for children and adolescents; paid parental leave for caregivers and a bonus equivalent to two minimum-wage salaries for unemployed parents; and creation of the National Childhood and Adolescent Cancer Program as well as a National Paediatric Cancer Registry.

**Philippines:** Two legislation landmarks in the Philippines contributed to incorporating cancer in UHC. In February 2019, The National Integrated Cancer Control Act (NICCA) strengthened cancer control, through the creation of the Philippines Cancer Center for research and training and the establishment of a population-based cancer registry. Since the adoption of the Universal Health Care (UHC) Act in March 2019, all Filipino citizens are automatically enrolled in the National Health Insurance Program, in addition to other reforms to the health system having been achieved through this same Act.



### 3.3

## PILLAR 3: REGIMENS OPTIMIZED FOR DELIVERY OF QUALITY DIAGNOSTIC AND TREATMENT SERVICES

### RATIONALE

**Context:** Access to cancer health products, linked to guidelines and protocols, is associated with higher cancer survival probabilities (153). There are two elements to consider in the effective implementation of Pillar 3 and to optimize outcomes, quality and efficient resource utilization: (i) production and use of best practice standards; and (ii) routine access to the specified products.

**Standards of care:** Effective provision of services for diagnosis and treatment starts by establishing standards of care that are linked to the system's ability to deliver the products and associated supportive care services as well as linked to the complex needs of children and their families (Box 11). Standards of care in oncology can be viewed through a broad lens and be related to national guidelines or recommendations, facility clinical practice guidelines, standard operating procedures for clinical interventions, workforce competencies, research protocols, or other accepted and defined practice according to a government recognized entity (154). Fundamentally, these standards serve the purpose of ensuring access to high-quality services, including research; currently, the lack of national standards of care negatively impacts access to quality medicines and technologies for childhood cancer and ultimately worsened outcomes.

**Essential products along the lifecycle:** Access to health products is further compounded by bottlenecks in access along the lifecycle or value chain (Figure 31). Common challenges in childhood cancer include poorly delivered or inappropriately prescribed treatment, substandard or falsified medicines, or stockouts of essential medicines and technologies. These contribute, in turn, to delays in therapy that affect outcomes, excessive rates of treatment toxicity, abandonment of therapy and death.

The delivery of high-quality childhood cancer products must, therefore, be ensured, with appropriate steps along the value chain, from research and development to procurement, adequate prescribing and safe disposal. Root causes analyses should consider availability, quality and affordability of products from both the supply and demand perspectives. Known barriers vary between medicine type as well as setting, though three common interconnected thematic areas exist:

### Box 11. Definitions of clinical practice guidelines, regimens and protocols

**Clinical practice guidelines:** Evidence-based statements that include recommendations intended to optimize patient care and assist health care practitioners to make decisions about appropriate health care for specific clinical circumstances. Clinical practice guidelines should assist clinicians and patients in shared decision-making (155).

**Regimen:** A treatment plan that specifies a structured sequence of treatment, its schedule, drug dosage and duration of treatment (156).

**Protocol (related to clinical trial):** A detailed plan of a scientific or medical clinical trial, experimental treatment or procedure.

- **Availability:** Manufacturers and suppliers are poorly incentivized by low profit margins and low volumes and are generally not answering the existing global demand, which may be limited and undersized. In some instances, specific paediatric formulations are required.
- **Purchasing and procurement** are often done at the facility level, or at levels disengaged from coordinated data inputs on actual demands and use. This is further negatively influenced by the specialized nature of regimen requests in childhood cancer, with unpredictable volumes and frequencies, particularly in centres unable to forecast needs and in countries with smaller populations. The consequence is frequent stockouts and shortages, in addition to potential mismatches between distribution sites and high-demand sites, increasing risks for point-of-care delays and expired medical products. The uncertainty of production volumes, timing of tenders, and potentially lengthy



and burdensome regulatory mechanisms all contribute to a particularly challenging market landscape.

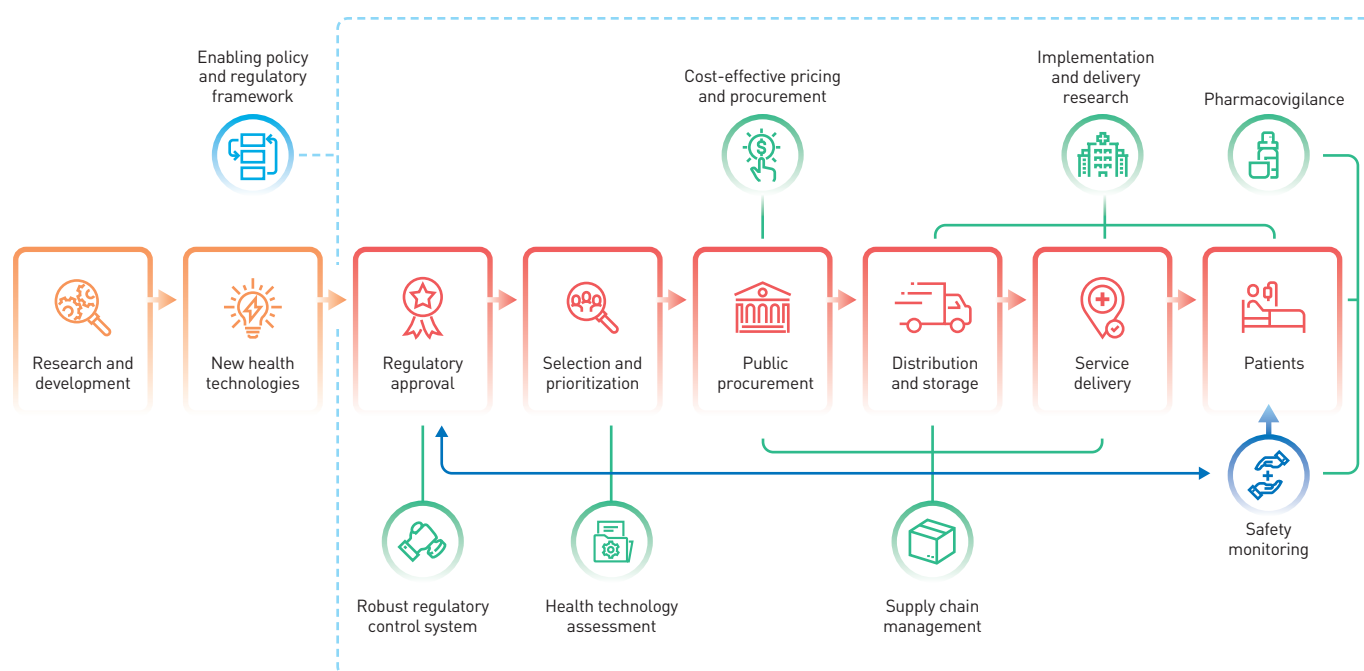
- **Quality:** multiple analyses have identified concerns for potential substandard products (defined as those authorized medical products that are either “out of specification”, or failing to meet either quality standards or their specification, or both) and falsified products (where products are deliberately or fraudulently misrepresented with respect to their identity, composition or source) in use for children with cancer. This includes a recent case study where a substandard product was associated with inferior outcomes and patient harm (157).

Affordability and acceptability are known critical variables impacting access to cancer medicines. The cost of childhood cancer medicines can be significant and result in delays as well as failures to initiate and/or complete treatment. Inclusion of childhood cancer medicines

in National EMLs and social insurance schemes/benefit packages can improve access to care and completion of therapy (see Section 3.2). Acceptability of cancer medicines can also be strengthened by social support programmes and family/patient engagement. These activities are generally tailored to the national context.

As of 2020, there are 14 childhood cancer-related tests on the WHO EDL; and 29 antineoplastic and related supportive medicines, 5 targeted therapies, 4 hormones and 1 immunomodulator for childhood cancer on the WHO EML. The vast majority of essential childhood cancer products are generic and generally inexpensive with well-established track records for safety. The quality of pharmaceuticals is important, and attention must be given to tracking efficacy.

**Figure 31. Steps in the life cycle required for the provision of high-quality childhood cancer products**



Source: WHO 2020 (56).

**Current situation:** Globally, the majority of countries do not have publicly available national standards or treatment protocols for childhood cancer care. In the WHO NCDs Document Repository, there are less than 10 national guidelines for childhood cancer(s) among the more than 200 documents submitted to WHO (158).

Deficits in the inclusion of childhood cancer in national guidelines or standards contribute to limited availability of services. For National EMLs, there is a bias against the inclusion of those defined by WHO as essential childhood cancer medicines. In a study analysing 135 countries, the median number of cytotoxic agents for childhood cancer listed in National EMLs was only 8 out of 18 assessed (159). This lack of harmonization results in facility-level procurement that

is more prone to supply chain disruptions, stockouts, high costs and potential exposure to substandard or falsified health products.

Two representative medicines that demonstrate complexities of access along the lifecycle of medicines are asparaginase and mercaptopurine. Asparaginase is included in the WHO EML for the treatment of acute lymphoblastic leukaemia in children. It is estimated that 40% of children with cancer will require asparaginase every year, yet there have been significant barriers to accessing asparaginase in countries of all incomes. Only 50% of National EMLs have included asparaginase in any of its forms (*E. coli*, *Erwinia* PEG-asparaginase), and shortages of and substandard asparaginase products have been reported (157).

Mercaptopurine (6-MP) is also included in the WHO EML for the treatment of acute lymphoblastic leukaemia and acute promyelocytic leukaemia, yet only 64% of countries have included it in their National EML (160). In addition, only one supplier is known

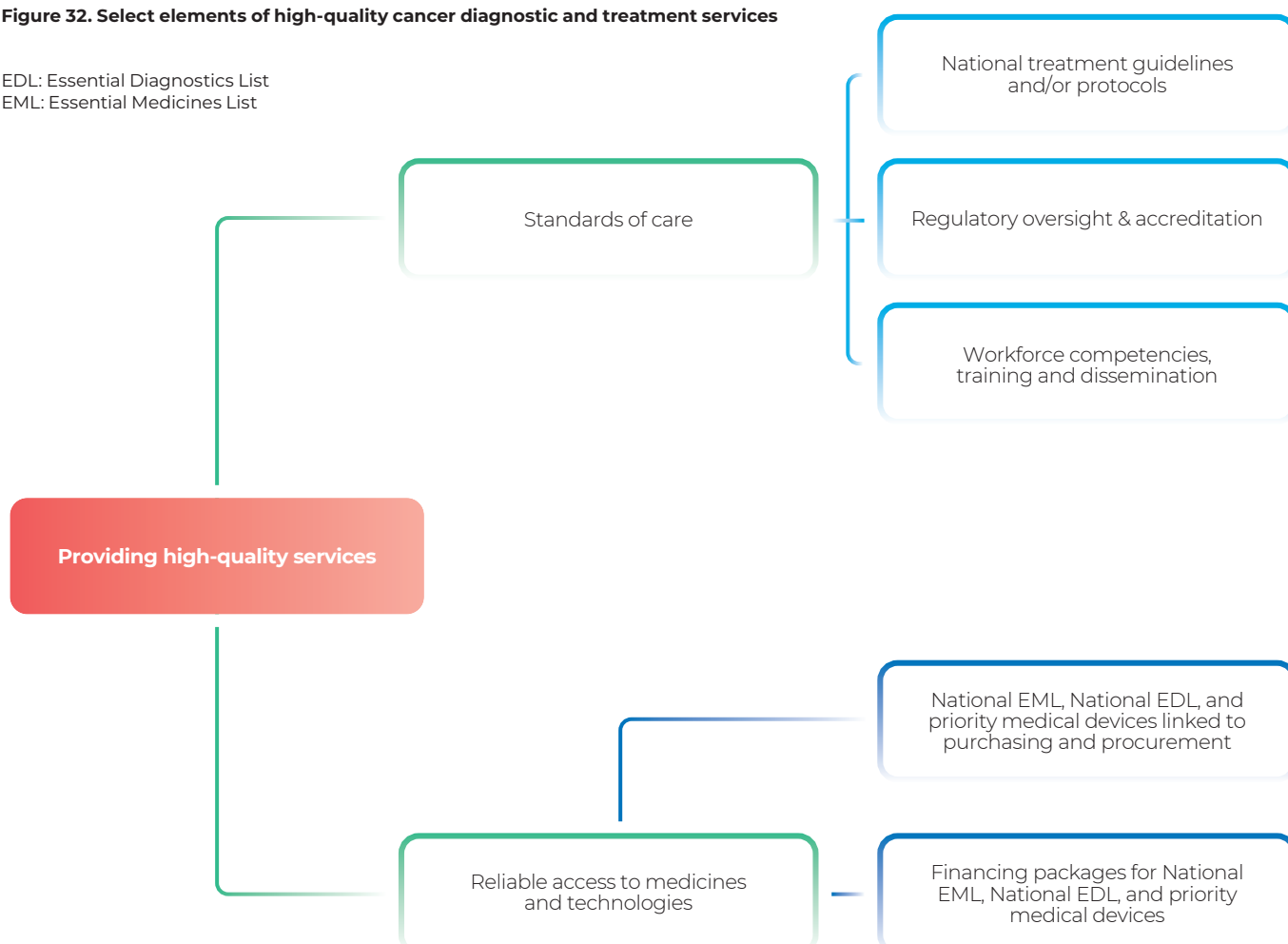
to produce a paediatric suspension, which is a liquid presentation more suited for young children. Shortages in countries of all incomes have been common. Additionally, a large variability in price ranges has been noted in LMIC (161).

## WHAT TO DO

National care standards should be developed, documented and utilized to inform the selection, purchasing and procurement of essential medicines and technologies. To ensure reliable access to childhood cancer health products, a measured approach should be implemented using interventions along the value chain (Figure 32). Hospital-based cancer registries recording the treatments administered will inform the hospitals on the needs, economy, comparison and evolution of treatment standards.

**Figure 32. Select elements of high-quality cancer diagnostic and treatment services**

EDL: Essential Diagnostics List  
EML: Essential Medicines List



### Priority action: Develop national standards of care for childhood cancer management

National care standards for common childhood cancers can improve quality of care and efficiency of product and service procurement. Selection of interventions should align with the development of essential interventions (see Section 3.2), with input from all key stakeholders, including community advocates. National standards can be developed for these essential interventions, including standard operating procedures for related clinical services as appropriate (e.g. safe handling and disposal of chemotherapy) (162).

For effective implementation, these standards should be endorsed by the relevant governmental authority and rolled out to all relevant facilities and cancer centres. Additionally, national standards must be linked to the system's ability to deliver care throughout its existing networks, including workforce capacity (see Section 3.1, Pillar 1) and capabilities to manage treatment-related toxicities.

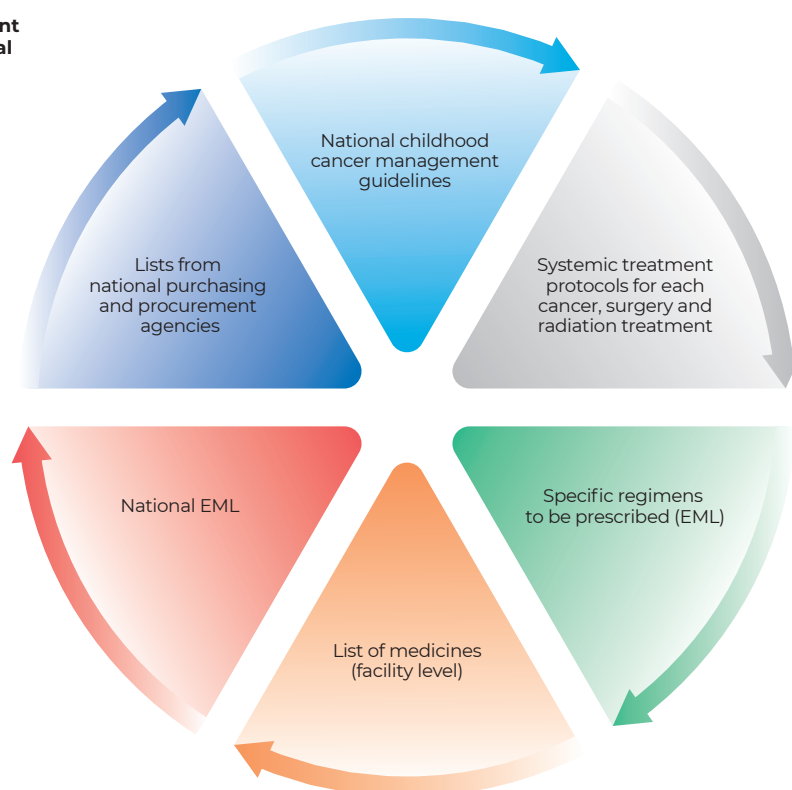
Standards should be linked to national policies and regulatory processes, when appropriate. For example, guidelines, protocols and regimens should align with National EMLs, standardizing procurement practices and addressing supply chain barriers. This increases policy coherence and ensures that national agencies can support the purchasing, procurement, pricing approaches and supply chain management for these medicines as important elements along the value chain (Figure 33).

Clinical practice guidelines must provide resource-appropriate guidance on all of the components needed to treat a child with cancer along the patient pathway from diagnosis to survivorship or palliative care and consider essential supportive care services and treatment-related toxicities (see Section 2.4). Management considerations, such as appropriately adjusting the intensity of therapy, can improve quality and adherence to best practices and increase overall survival by reducing treatment-related toxicity.

Clinical practice guidelines must also be linked to broader health system capacity and included in a national dialogue related to childhood cancer programmes. For example, delivering highly intense chemotherapy in a setting where a functional blood bank or broad-spectrum antibiotics are not available may result in higher rates of morbidity and toxic death, ultimately causing more harm. As such, before advancing in treatment complexity at the facility level, a checklist of readiness can be used, which should be mediated through a national dialogue.

Standards for safety, including infection prevention and control, safe handling, administration and disposal of chemotherapy should also be promoted, and can be done through national regulatory efforts and/or promoted through facility-level quality assurance programmes. Other important safety-related standards of care to include in quality guidelines for complex treatment procedures are safe administration of high dose methotrexate, adaptations to the delivery of radiation therapy for children and complex surgical procedures and anaesthesia.

**Figure 33. Ensuring alignment between guidelines, National EML and procurement lists**



## Priority action: Ensure reliable supply of quality cancer products for treatment of childhood cancer

Quality cancer products required for the treatment of childhood cancer include essential medicines and technologies, such as those required for radiotherapy. The prioritization and pricing of particular health products, and their inclusion in a cancer benefit package or cancer care system, can be systematically evaluated through a formal health technology assessment (HTA) process, separately or together with a cost-effectiveness analysis.

**Medicines:** National EMLs should align with the WHO EML for Children (7th edition 2019) to facilitate selection and procurement of essential medicines (144). These should include anti-neoplastic drugs as well as crucial supportive care medicines, such as anti-emetics, antibiotics, analgesics and laxatives. National EMLs can be used by national procurement agencies to select medicines and for planning and by facilities and providers to ensure coherency with treatment regimens, selecting medicines that make the basis of national guidelines. Product procurement for cancer must also include the need for paediatric formulations (oral suspensions) and for ensuring adequate supply to complete long treatment courses. United Nations procurement mechanisms can support access to childhood cancer products (Box 12).

Quantities can be informed by predicting volumes based on caseloads, modelling unmet needs and anticipated volume, and/or benchmarking. This should be re-evaluated frequently, as the number of patients may grow, particularly as availability of and access to services increase.

Market dynamics must also be considered given the small volume of patients, particularly in smaller countries, and limited revenue incentives. For purchasers, it is important to consider the quality of medicines, which can translate to efficacy and affordability. A dialogue with suppliers can help anticipate demand and foster a meaningful dialogue about short- and medium-term needs.

**Medical devices:** Similar to medicines, access to medical devices requires a stepwise approach: needs assessment; defining specifications of proposed products; and procurement, including use of effective pricing approaches, regulation and maintenance. Maintenance can further be divided into calibration, maintenance, repair, user training and decommissioning.

Equipment selection must begin with the needs assessment and identification of the required equipment to deliver defined essential services (Table 6). Planning is informed by the geographic distribution of the country and disease burden, the particular needs of children and the capacities of existing facilities or need for new facility growth.

Access to equipment must be linked to quality assessment programmes, both internal and external. Maintenance of equipment and technology, with service contracts or in-house repair teams, should be integrated upfront into the dialogue with manufacturers, to allow for quick turnaround of repairs of damaged equipment.

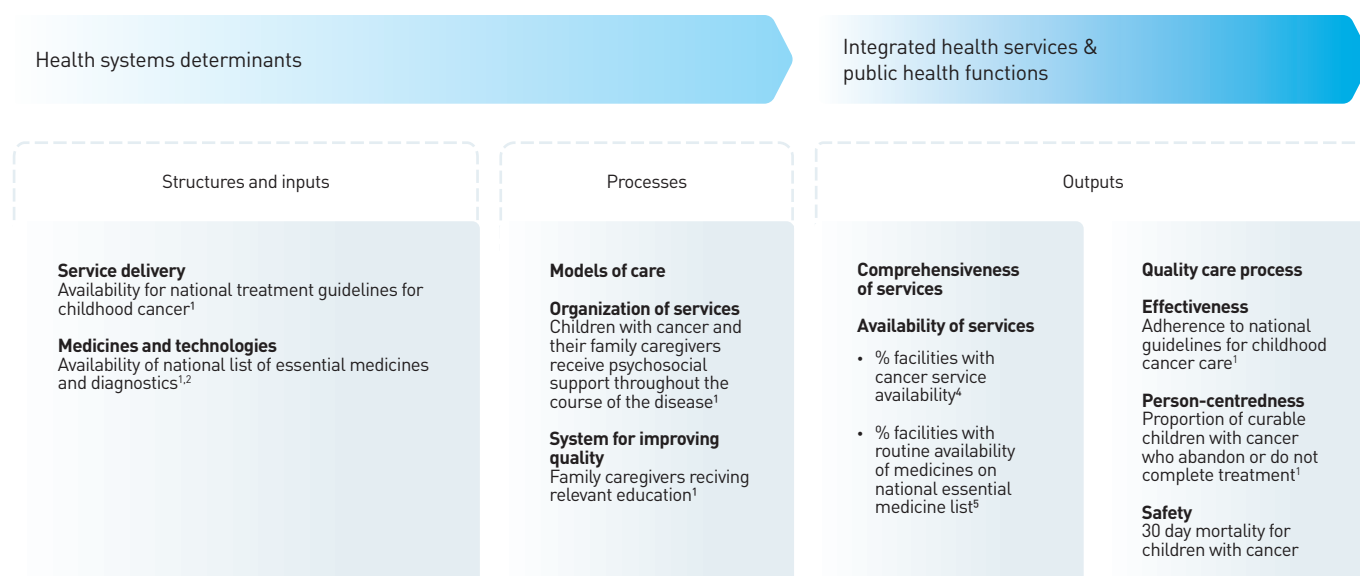
**Table 6. Examples of equipment required for the treatment of childhood cancer care**

Systemic therapy	Safe prescription (dosing by weight or surface area); preparation, administration and disposal of chemotherapy, including a designated chemotherapy preparation area, preferably with a biosafety cabinet class II (163,164); availability of personal protective equipment (pharmacy, nursing); IV pumps and central catheters; appropriate disposal of biological and chemotherapy waste according to international standards for LMIC (165).
Radiotherapy	Simulator, cobalt-60 unit, linear accelerator, other therapies such as proton or brachytherapy, mould room, treatment planning systems, immobilization devices for children.
Supportive care and palliative care	Basic devices and technologies for measuring nutritional status (weight, height and mid-upper-arm circumference as minimum measurements). Purchasing and procurement of ready-to-use therapeutic foods (RUTF) as well as in-patient nutritional supplements, acknowledging that local formulas and recipes are the most sustainable and easy-to-access sources of nutrition. Access to quality and timely blood bank services, antimicrobials (bacterial, viral and fungal) and analgesics (anti-inflammatory, narcotics and sedatives). Subcutaneous infusers, patient control devices (PCA) and other parenteral analgesic devices.

## SAMPLE METRICS

Figure 34 outlines sample indicators relating to delivery of quality diagnostics and treatment services.

**Figure 34. Metrics for delivering quality diagnostic and treatment services**



Sources: 1. WHO 2006 (124); 2. WHO Regional Office for the Eastern Mediterranean 2017 (125); 4. WHO 2014 (127); 5. Vasquez et al. 2021 (52).



Ester Demirtshyan, Armenia

## CASE STUDY

### Box 12. Improving access to medicines

The Pan American Health Organization (PAHO) Strategic Fund for essential medicines is a regional technical cooperation mechanism for pooled procurement of essential medicines and health supplies. Its objective is to improve access to quality, safe and effective medicines, ensuring affordability while promoting efficient and sustainable health systems.

Trinidad and Tobago is a member of the Caribbean Childhood Cancer Network and initiated **CureAll** country implementation by prioritizing cancer registries and promoting integration of childhood cancer into national health policies. After an analysis revealed unreliable drug procurement and lack of pharmacovigilance, one of the areas identified for improvement was the access to national essential childhood cancer medicines. Through the PAHO Strategic Fund, the Network was able to address barriers in access to medicines by establishing twinning procurement programmes between large and small markets, by implementing digital inventories allowing for improved data collection and by training pharmacists in quality assurance.

Source: Preston 2020 (166).



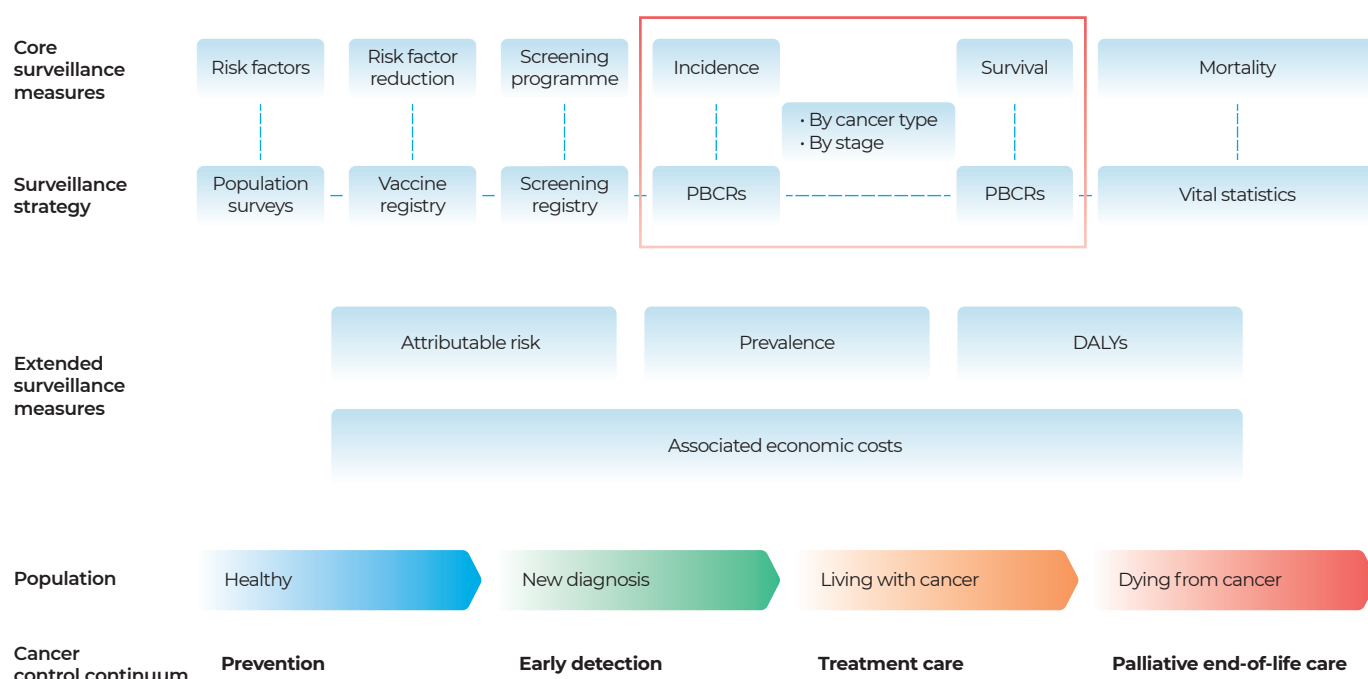
## 3.4

# PILLAR 4: EVALUATION AND MONITORING WITH INFORMATION SYSTEMS TO IMPROVE OUTCOMES

### RATIONALE

Robust health information systems (HIS) are fundamental to planning cancer control, monitoring the performance of programmes and evaluating areas for targeted action by converting data into information for health-related decision-making (Figure 35) (167).

Figure 35. Research domains from basic and advanced data-enhanced cancer registries



Source: WHO 2020 (6).

DALYs: disability-adjusted life years  
PBCRs: population-based cancer registries

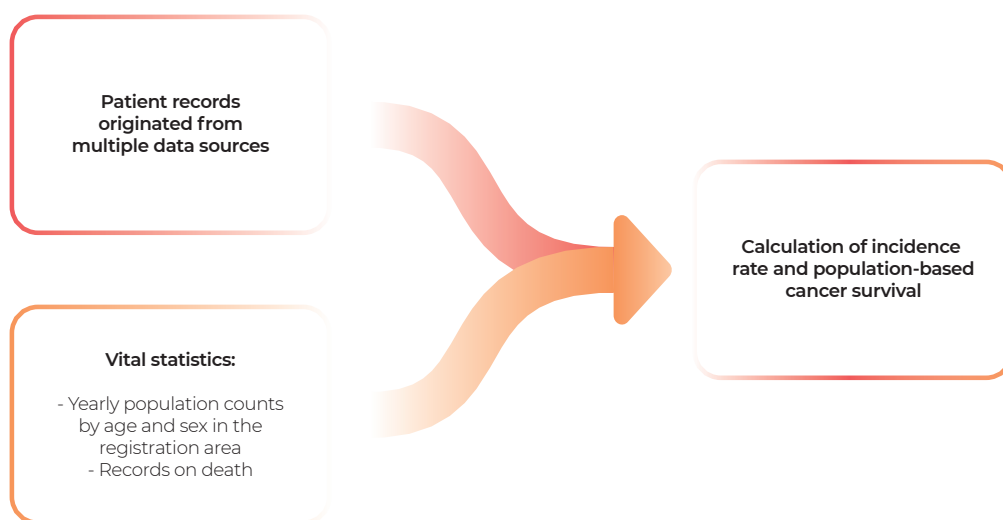
**Population-based cancer registries (PBCRs):** PBCRs generate data on a population level. They are the source of data necessary to plan, establish, monitor and evaluate cancer control programmes.

PBCRs cover a defined population in a country or region and describe the extent of cancer burden in that population, in terms

of the number of cancer cases and frequency of disease occurrence (cancer incidence), in each age, sex and period and by cancer type. If information on the vital status of the registered patients is also recorded, then the registry can describe cancer survival in its reference population (Figure 36) (167).



**Figure 36. Data sources for PBCRs**



The data quality depends on the quality of information in the sources identified in Figure 36, skills and number of cancer registrars collecting and processing information, the possibility of linkage to other databases, implementation of validation procedures and involvement in international collaborative studies.

The principal asset of a PBCR is a high completeness of registration, aiming at recording 100% of cancers having occurred in the covered population. Quality control (168) and evaluation of completeness (169) are a part of good quality registries and are the criteria for inclusion in international comparative studies (23).

The burden of cancer in children is measured in two types of PBCRs, both of which can provide quality data on childhood cancer, given required resources and a legal mandate:

- Paediatric cancer registries, which cover the population aged 0–14 and 0–19 years, are known to be linked closely with professional societies of paediatric oncologists and haematologists, often the originators of these registries.
- General cancer registries, which register cancers occurring in the entire age span, including in children, often provide the advantage of having a legal framework, a more formal funding scheme, easier access to other vital databases and established data flow enabling a long-term follow-up.

A comparable legal mandate and collaboration between both types of registries, where they coexist, can improve effective implementation. Indeed, in some countries, legal requirements surrounding data collection do not permit paediatric cancer registries to establish themselves as a reference source of data on

cancer burden in children. Such restrictions are generally detrimental to cancer control policies in childhood populations, as paediatric registries may provide authoritative information, such as delays in diagnosis, staging and treatment.

**Hospital-based cancer registries (HBCRs):** Data from HBCRs, in contrast to data from PBCRs, describe the groups of patients diagnosed or treated in a specific treating centre, therefore, relying on a single source of information (170).

While HBCRs cannot generate relevant information on cancer burden in a population, they can provide detailed information on cancer diagnosis, treatment, outcome and short- to medium-term clinical follow-up for each treated cancer patient. Information generated by HBCRs serves to direct and manage the hospital or treatment centre, and evaluate treatment (170). HBCRs are established and supported by the hospital.

The differences in the aims, data sources and output between PBCRs and HBCRs mean that one cannot play the role of the other (171). HBCRs are an extremely useful data source for PBCRs if the data can be linked. Results generated by PBCRs provide a useful feedback to all data providers, including HBCRs. The principal differences between these two complementary registries are shown in Table 7.

**Table 7. Comparison of the principle, setting and scope of action between population-based cancer registries (PBCRs) and hospital-based cancer registries (HBCRs)**

	Population-based cancer registries	Hospital-based cancer registries
Aim	To assess the impact of cancer on the covered community	To evaluate clinical care in the hospital
Population	Well-defined and enumerated	Unknown, based on referral area
Data sources	Hospital departments (oncology units, pathology departments, radiotherapy departments, haematology laboratories, paediatric wards) Autopsy reports Outpatient clinics Laboratories Death certificates General practitioners Screening programmes Health insurance companies Population registries Hospices	Hospital departments Autopsy reports Outpatient records Hospital laboratories
Registration process	Notification from data sources Active case finding	Records of care
Data items	ID/contact information of patient Demographic/exposure data Disease (basic) Treatment (basic) Follow-up/outcome long-term	ID/contact information of patient Hospital/history of stay Disease specific to children (extended) Treatment (extended) Follow-up/outcome short-term
Occurrence measure	Frequency of cancer types in a population Incidence rates	Case reports Frequency of cancer types among patients
Outcome measure	Population-based survival (mortality rates)	Evaluation and comparison of therapies
Timeliness	Reporting within 1–5 years after diagnosis	In real time
Use of data	Community cancer control Aetiology research	Hospital cancer programme Comparison of therapies
Ownership support	Governments Public bodies (nongovernmental organizations)	Hospital

In populations with a single referral hospital, the data from an HBCR may approximate data from a PBCR, although the case ascertainment will likely be incomplete and frequency of cancer types potentially biased. An HBCR can supplement a PBCR with data, but cannot replace it; HBCRs and PBCRs have complementary functions (171,172).

HBCR data allow stakeholders to monitor services, including treatment outcomes, toxicities and abandonment, and assess performance on the level of facility. Information generated by HBCRs serves to train and build capacity in paediatric oncology. The use of HBCRs can also serve as an introduction to capacity-building in data registration (173).

### Cancer registries at the basis of information system for the design and implementation of cancer control

Cancer registries are integrated into broader information systems to support monitoring, quality assurance, research, programme management and policy formulation. PBCRs must be supported by national or subnational governments so that they can be sustained in time. The registry activities should be steered by a committee composed of stakeholders representing the profession, academia, policy and patients.

Presentation of data on childhood cancer is determined by substantial differences in the distribution of cancers by age. Cancers occurring in children represent a very small proportion of all cancers in a population and the principal cancer categories are dissimilar (172). Additionally, as childhood cancers cannot be prevented or screened for, registries must focus on accurate diagnosis and staging. These differences require a separate reporting of cancer burden in children, according to the diagnostic groups defined in the International Classification of Childhood Cancer (23), and using ICD-O-3, revised in 2017 (the second revision, ICD-O-3.2 is due to be released in summer 2021). Specific recommendations have

been developed to ensure standardized recording of stage and non-stage prognosticator data to be collected in PBCRs for the majority of cancer types occurring in childhood. These have been adapted to resource-limited settings and implemented in several LMIC (154–156,174).

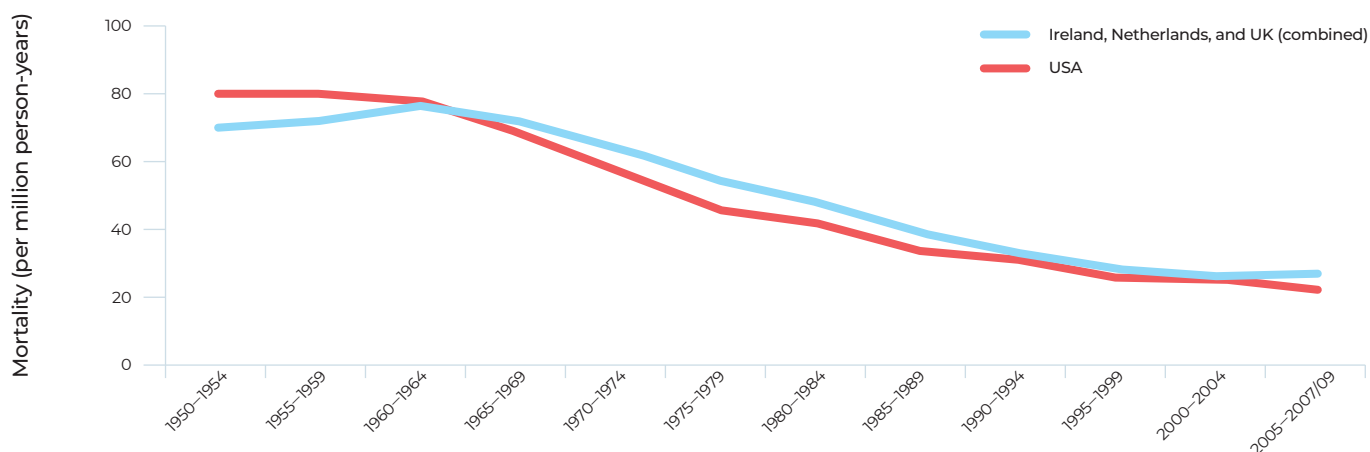
Population-based estimations of incidence and survival define the needs and allow comparisons across settings and over time. They are also indicators of access to and quality of treatment on a population level. They support evidence-based decision-making and have been linked to improved population cancer outcomes by providing information needed for planning and evaluation of cancer control programmes, and serving as a basis for research (169). The lack of population-based data is a barrier to the development of national political priority and policy for cancer control (167). Models developed based on existing cancer registries can also help forecast expected changes in cancer incidence based on demographic shifts and diagnostic capabilities.

Yet, the number of cancers occurring in childhood population may be considerably higher in some settings (175) and has been modelled to represent more than double of the registered cases in parts of Africa (17). The potential underestimation of cancer incidence may be due to unawareness, underdiagnosis, misdiagnosis or limited access to health care. It is important to tackle these issues, especially in the areas where childhood cancer is still stigmatized and considered a fatal disease, so that all patients have equal access to care (33).

### Information systems supporting research and innovation

In childhood cancer, investments in research have been responsible for a better understanding of childhood cancer and significant improvements in health outcomes. These remain a priority to drive innovation and improve quality of care (Figure 37) (176).

**Figure 37. Childhood cancer mortality (aged 0–14 years) in three European countries and the United States**



Source: Pritchard-Jones et al. 2013 (176).

International collaborative research involving all sectors leads to a better understanding of childhood cancer epidemiology and treatment, adaptation of standards of care in LMIC, improvement of outcomes and to gain of knowledge in paediatric oncology (43). In particular, the use of evidence-based adapted management guidelines must be prospectively evaluated in LMIC to document their efficacy and adapt them based on findings.

PBCRs can offer an understanding of the unique distribution and survival of childhood cancer across geographical regions, which can serve as a basis for further epidemiological research (177). Discovery of biological and genetic differences by region or race can inform about differences in outcomes. Strong HIS includes additional parameters, such as treatment facilities, medications, palliative care; and facilitate health service research, implementation science and clinical trials. Together, these types of research help answer clinical questions to accelerate improvements in the care for children (178). Currently, however, the vast majority of such research occurs in HIC (43,179,180).

In addition, research plays an important role in the policy process, as data collection can identify issues and help prioritise them, inform decision-making and then monitor impact of interventions (181). As such, research constitutes one of the key action points to drive the fight against cancer.

**Data privacy:** Global research requires global data sharing. This requirement is challenged by national regulations restricting data transfer for international studies in an increasing number of countries. International studies have been shown to improve data quality in local data sources (23), but such improvement is only possible if access to individual cancer records is allowed and data are shared. This is particularly important in paediatric oncology, where national research is based on much smaller data sets than those available for cancers in all ages.

However, this must be balanced with patients' privacy preservation. In effect, there are potential individuals' risk of data breach or data misuse, particularly in settings where data security and privacy are not maintained, or where data ownership is not defined (182). Data privacy must be ensured through the implementation of appropriate policies and strong data governance, balanced with appropriate data retention and access to data (183). Frameworks for data governance ensure data privacy and safety, highlighting the importance of ethical oversight and informed consent; data protection through data access controls; sustainability of ethical data use allowing long-term data storage; and application of relevant protection legislations (182).

Individual rights and data privacy must be balanced with sharing data on the international level, to stimulate progress that can only be achieved on a global level.

**Information systems and quality assurance:** Information systems are also important to provide a platform to support adapted management guidelines for all major tumour types (see Section 3.3, Pillar 3), including guidance for all components needed in the care of a child with cancer.

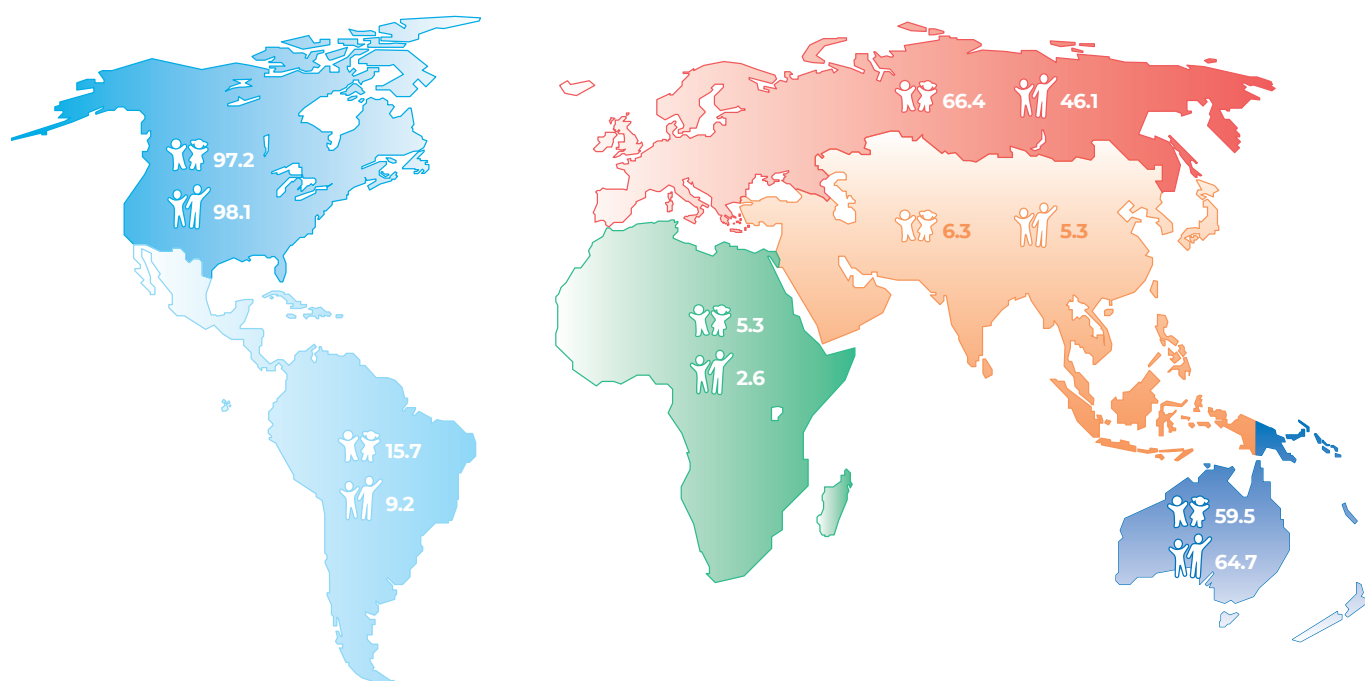
Electronic medical records (EMRs) systems are useful tools that collect patients' clinical information and comprise the capabilities needed to deliver health care, allowing health providers to document, monitor and manage patients. They can also embed best-practice guidelines and different specialist clinical modules (e.g. paediatric oncology and chemotherapy prescription systems). EMRs, however, are different from PBCRs and HBCRs, given the data are not entirely codable, can be entered by any provider and serve mainly clinical purposes. In contrast, registries collect data that are clean and analysable. EMRs, albeit important for safe clinical care, can therefore not replace PBCRs and HBCRs.

**Indicators to monitor quality of care:** Information systems for cancer include additional data beyond those collected in cancer registries. These additional data serve many functions, including planning cancer programmes and monitoring of their performance by assessing key domains at the population, facility or community level. These core indicators serve as a basis for quality improvement (QI) efforts and should be defined by national policy-makers and programme managers. Agreeing on a set of indicators allows stakeholders to assess cancer systems and programme implementation across different settings.

**Current capacity:** In most countries around the world, cancer registries do not exist and where they exist, they often struggle with limited resources and uncertain sustainability, putting in peril all data collected in the past (Figure 38).

The true extent of the childhood cancer burden is unknown in many LMIC, where cancer data are not systematically collected. Furthermore, even in the presence of PBCRs, information collection on young populations is often neglected or challenged because of the proportionately smaller number of childhood cancers and additional resources required to ensure its data quality. Approximately, only one tenth of the global population aged 0–14 years (11.4%) was covered by cancer registries in 2000–2010, with a regional variation of 1.7% in South Asia (India) to 99.4% in North America (184).

**Figure 38. Proportion of childhood population that provides PBCR data by continent (2010) to comparative international studies**



Source: Steliarova-Foucher et al. 2017 (23).



Children (age 0–15 years)



Adolescents (age 15–19 years)

Other sectors of HIS, indispensable for a solid cancer control plan, include quality vital statistics. Given the population movements and incomplete registration of births and deaths, good data on population size are still a challenge in some areas. Regarding mortality data, only 34 of 178 Member States provide data on causes of death to WHO. This number includes 21 of 47 LMIC and only 4 of 34 LIC (25). As death is one of the cancer outcomes, national registration and centralization of information on causes of death contributes to cancer control, along with control of other diseases. Mortality statistics is one of the milestones on the way to cancer elimination.

**Data on childhood cancer research:** Improved outcomes in childhood cancer are directly linked to cancer research yielding scientific discoveries, innovation and advancements in clinical practice. Yet, childhood cancer is still underrepresented in the research agenda. A bibliometric analysis of global oncology research showed that only 5% of articles published related to childhood cancer (185). In addition, the geographical distribution of childhood cancer research is inequitable. A study conducted between 2008 and 2016 showed that 77% of the global funding for childhood cancer research (totalling US\$ 2 billion) was awarded from and to United States institutions, and only 5% was directed towards health care delivery research (152). Finally, the vast majority of such research occurs in HIC, with, as an example, only 12% of African oncology

studies including children and adolescents (186). While a larger number of African countries have reported having active research programmes, this highlights the scarcity of cancer research in LMIC (187).

## WHAT TO DO

Information systems used for monitoring and evaluating cancer programmes should include data at the national, facility and community levels and should be based on agreed datasets to promote comparability between settings and regions.

### Priority action: Strengthen cancer registries and related cancer information systems

The objective is to establish population-based cancer registries as part of a fully functional and applied cancer information system. In addition, implementation of HBCRs is highly encouraged in all paediatric cancer units using standard registries that can capture basic treatment data as well as follow-up information on patients to measure survival and track abandonment (20).

Robust political commitment is required, linked to other relevant government agencies and legislative tools. For example, two relevant policies that can strengthen HIS are: (i) legislations listing cancer as a reportable disease; and (ii) well-structured regulatory frameworks behind information sharing.

Public funding, using domestic budgets, must be allocated to data collection as well as to platforms for compilation, analysis and synthesis – this includes the infrastructure, personnel and devices required for each step.

Although countries and facilities will have different starting points and thus different approaches to strengthening information systems, the following principles apply:

- Enact policies, legislation and regulatory measures to support strengthened HIS and data sharing.
- Strengthening of information systems should be done in a progressive manner, starting by building on existing HBCRs, working towards subnational PBCRs and then expanding to national PBCRs, noting this should not be done at the expense of sustained HBCR investment. PBCRs can then be expanded as the country's registry capacity increases to include broader datasets and systems and more refined data items (see next Priority action).
- Yearly vital statistics should be collected (civil registration and vital statistics [CVRS]) at the national and subnational level, by sex, single years of age and ethnicity. CVRS should be linked to PBCR to capture data on mortality and survival.
- Data should be collected using cancer categories that are relevant to childhood cancers within ICD-O-3, and outcomes should be reported using the third edition of the International Classification of Childhood Cancer groupings (ICCC-3); ensuring leukaemias and lymphomas are reported separately and central nervous system tumours are reported by grading (188).
- Frameworks can be formulated to encourage data sharing between HBCRs and PBCRs on a national level.
- As much as possible, aim to pool data from varied populations and promote international data sharing with global burden estimation and other research groups (20).
- Using data for research will accelerate local, regional and global progress.
- Ensure capacity-building of a workforce not only to collect data, but also to compile, analyse and synthesize data to better inform decision-making. Cancer registration training curricula must be created and disseminated. Adequate training is crucial to ensure quality of data collection and analysis, in adherence with national and international standards.
- Interpretation of local data should be done locally as much as possible, avoiding externalizing data analysis.

To facilitate this process, networks of implementing partners can support countries looking to build capacity in registries as well as for training in data collection in HBCRs and PBCRs (Box 13) (189).

### **Priority action: Define core indicators and utilize a monitoring framework for quality improvement (QI) measures**

A set of standard principles, methods, definitions and recommendations exist to help all PBCRs, as part of broader health information systems, to achieve international standards in their operations (23,168–170,174,190–192). The minimum standard data set is well defined and contains as few as 10 variables permitting to provide data on cancer incidence. Depending on the cancer registry mandate and resources invested in cancer registration, this can be expanded to include additional data items (e.g. information on follow-up, staging, treatment, late effects, predisposing characteristics, exposures).

Developing standards in childhood cancer management delivers on all six dimensions of the WHO definition of the quality of care (Figure 39). Quality should be managed by policy-makers, health service providers, including nurses and physicians as well as community and service users, as co-producers with distinct roles and responsibilities.

Indicators should be selected to monitor implementation of programmes, with a particular focus on quality and coverage. They should be relevant to the national programmes and priorities, scientifically sound, evidence-based, applicable to users and sustainable. Since the status and functions of information systems differ between countries, national policy-makers and programme managers, in collaboration with the field, should determine the indicators to be monitored in their particular context, with an understanding of how those will support monitoring and evaluation, planning and QI functions.



**Figure 39. WHO dimensions of cancer care**

Effective	Efficient	Accessible	Acceptable and patient-centred	Equitable	Safe
Evidence-based care results in better outcomes	Delivery of care so as to maximize use of resources and avoid waste	Delivery of care that is timely, at a reasonable distance and with appropriate skills and resources	Delivery of care according to the preferences and aspirations of people living with cancer and local culture	Delivery of care of the same quality for all	Delivery of care that minimizes risk and harm to people living with cancer and others
<b>Examples of low-quality care</b>					
Inadequately trained surgical workforce resulting in positive surgical margins	Inappropriate selection of medicines on National EML	Overly centralized system not accessible to geographically remote communities	Failure to include child or family perspective in decision-making	High out-of-pocket payments	Treatment-related toxicity because of poor infection prevention and control
Unavailable or unused treatment guidelines or standards	Screening for childhood cancers with no benefit, high rate of overdiagnosis, overtreatment		Poor communication of outcomes or prognosis	Discrimination by gender, age, race, religion or other characteristics	Unsafe handling or disposal of chemotherapy Lack of nuclear safety
<b>Examples of national strategies (beginning with assessment and coherence with broader strategies)</b>					
Accreditation of facilities and providers	National standards of care	Strengthen referral pathways, build specimen transport networks	Engage cancer survivors and civil society  Measure patient-reported outcomes and experience	Focus on UHC and customized programmes for disadvantaged populations	Set up or strengthen appropriate regulatory agencies and/or functions
<b>Examples of facility-based interventions</b>					
Invest in in-service training	Use high-performing teams	Coordinate care within care network	Strengthen cadre with competence in patient navigation, psycho-oncology	Train staff in communication	Set up QA teams and platforms

Source: Adapted from WHO 2006 (193).

QA: quality assurance

## Priority actions: Invest in cancer research infrastructure and participate in collaborative research networks

Focusing on research should be a long-term strategy and priority, as this yields broader benefits for countries of all income levels. It requires sustained investment.

Research capacity-building should be viewed as incremental, using a stepwise approach progressing from monitoring adherence to guidelines and implementation science (QI), to simple research protocols such as single-arm studies and finally, to more complex research design, including international epidemiological studies, randomized clinical trials and biological studies.

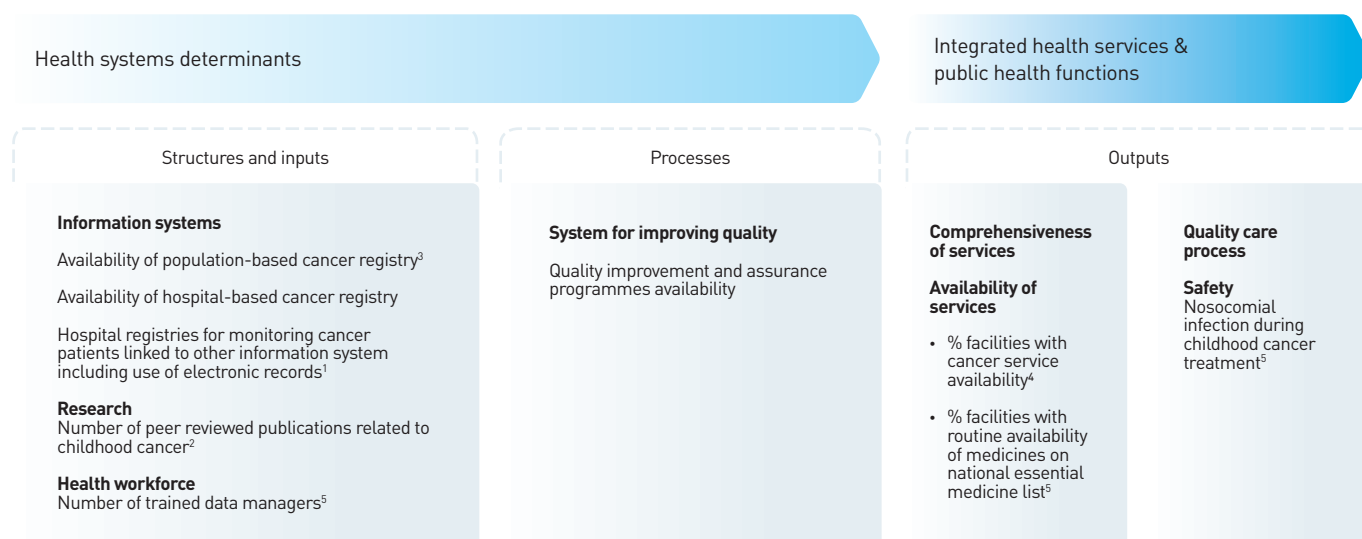
Throughout this process, the following elements are key considerations:

- Collaborative networks and partnerships at the national, regional and international level are critical for successful research.
- Local research should be promoted, which includes priority setting driven by local experts and synthesis of data and interpretation.
- Development of local research capacity among health care providers, as well as capacity-building and training of data managers and research associates, should be ensured, which can be supported by existing networks and partnerships.
- Ensuring processes are established for data collection, analysis, quality and safety.
- Ensuring ethical principles are respected, and ethics committees and developed.

## SAMPLE METRICS

Figure 40 outlines sample indicators for monitoring and evaluation.

**Figure 40. Metrics for monitoring and evaluation**



Sources: 1. WHO 2006 (124); 2. WHO Regional Office for the Eastern Mediterranean 2017 (125); 3. WHO 2021 (126); 4. WHO 2014 (127); 5. Vasquez et al. 2021 (52).

## CASE STUDY

### Box 13. Childhood cancer registration

Cancer registries are essential elements for the planning, implementation and evaluation of comprehensive cancer control programmes. In LMIC, there are significant inequities in access and quality of cancer information. In the Central America 4-region (CA-4), comprised of the four countries that belong to the Central America Integration System (SICA), El Salvador, Guatemala, Honduras and Nicaragua, efforts to develop PBCRs are being carried out with collaboration from international and academic partners. Initial efforts to create PBCRs started in 2014 with the collaboration of international partnerships

from the Dana Farber Cancer Institute, St. Jude Children's Research Hospital, the Union for International Cancer Control (UICC), the International Atomic Energy Agency (IAEA), the National Cancer Institute (NCI), and regional academic partners from the Central American Association of Paediatric Hematology Oncology (AHOPCA) network. The methodology to create PBCRs included training cancer registrars in coding practices, cancer registration software and through policies and procedures. This PBCR initiative in the CA-4 has contributed to launching regional cancer control initiatives.



## 3.5 ENABLERS

**CureAll** enablers – advocacy, governance and financing – are the foundation for multisectoral action facilitating implementation of the four pillars and strengthening the broader health system. These three

enablers are interconnected and must be coordinated to ensure sustainable national comprehensive childhood cancer programmes.

### 3.5.1 **ENABLER 1:** ADVOCACY

Advocacy generates political will and facilitates implementation. The childhood cancer community has a rich history of mobilizing political, social and cultural capital to drive progress and promote access (194).

**What are the components of advocacy?:** Effective advocacy encompasses stakeholder engagement, coalition-building and empowering of local champions to facilitate context-appropriate messaging (4,195). Stakeholder engagement and successful coalition-building is a multistep process that includes early dialogue with multisectoral actors (particularly, children and parent support groups), mapping of existing networks and platforms, and then engaging these relevant stakeholders with defined terms of references. An open and effective dialogue defines key actions, in accordance with mandates, promotes accountability and transparency, and allows for routine monitoring of potential conflicts of interest. Roles and responsibilities of civil society can also be delineated in a national cancer plan (see Section 3.5.3).

Empowering local champions and cancer survivors enables them to share stories, which is one of the most powerful ways to reduce cancer stigma, raise awareness, promote equity and access to services, and encourage care-seeking (136). Including childhood cancer survivors into organizational governance ensures that their needs are at the centre of policy-making, service delivery, research, information and support.

A rich community of childhood cancer organizations already exists at multiple regional, national and global levels. Nascent civil society organizations can utilize these networks to adapt established effective messages to local contexts and for different media platforms. Opportunities for engagement exist in both health and non-health sectors.

#### **Role of advocacy and civil society in childhood cancer care:**

There are three domains in which civil society can advance the implementation of cancer control programmes (Table 8) (6).

First, advocacy can play a major role in advancing childhood cancer as a public health priority through outreach campaigns and lobbying for political action (see Section 3.5.3). Second, convening leaders and national coalitions can also support priority setting and participatory multisectoral engagement. Finally, civil society organizations can meet children and family's needs before and during treatment by providing psychological support, offering housing and providing supportive care services (Box 14).



**Table 8. Roles of advocacy in childhood cancer care**

Domain	Role	Actions
Political advocacy	Accelerating policy-making	Generating political will to formulate childhood cancer control programmes, strategic planning and resource allocation.
	Assisting in strengthening capacity-building	Advocating for comprehensive services and workforce training to meet the needs of children with cancer, including supportive care, psychosocial and nutrition care, and others (e.g. housing, transportation).
	Resource mobilization	Fundraising through organizing events and engagement with private philanthropic foundations.
Convening	Developing campaigns for early cancer diagnosis	Creating awareness through campaigns on signs and symptoms of childhood cancer targeting the general public, primary care providers and community health centres.
	Accelerating research	Highlighting research priorities, advocating for financial allocation for childhood cancer research and pushing for scale-up of access to clinical trials.
	Reducing stigma	Context-appropriate messaging delivered by survivors to reduce stigma and dispel myths; encouraging care-seeking behaviour in contexts where childhood cancer is unknown or thought to be incurable.
Child and family support	Access to medicines and technologies	Advocating for sustainable access, including monitoring for stockouts and/or substandard or falsified products.
	Information	Creating evidence-based information for families and children on the cancer journey.
	Practical support	Providing support to families for housing, transportation and meals.



Shut Svitlana, Charitable Fund "VIDEN", Ukraine

#### Box 14. Political will and community advocacy to prioritize cancer control in national health strategies

Morocco has a long-standing commitment to cancer control as part of a national multisectoral response for NCD prevention and control, most recently reflected in the development and implementation of the first National Cancer Prevention and Control Plan (NCPCP) (2010–2019). In September 2019, Morocco sent a formal request to be considered as one of the Global Initiative for Childhood Cancer focus countries. Through the collaboration between the Lalla Salma Foundation and Morocco's Ministry of Health, a second NCPCP 2020–2021 was set up, initiated with an overarching goal to achieve at least 80% survival rate for childhood cancer and ensure the diagnosis and treatment of 100% of cases by 2030. Morocco's NCPCP, developed in consultation with a wide range of national and international stakeholders, is organized around four main strategic axes: epidemiological surveillance of

childhood cancer; quality assurance for all aspects of childhood cancer management; strengthening availability of drugs and products for paediatric haematology oncology; and development of supportive and palliative care for children with cancer.

Continued progress to roll out the Global Initiative for Childhood Cancer in the Eastern Mediterranean has been successfully achieved with the first stakeholder regional consultation, conducted in January 2021 with the participation of over 100 government and non-state actor representatives. The consultation aimed to outline a regional governance structure and partnership model that will contribute to providing financial and technical support to strengthen national health systems to provide quality of care for childhood cancer in the region.



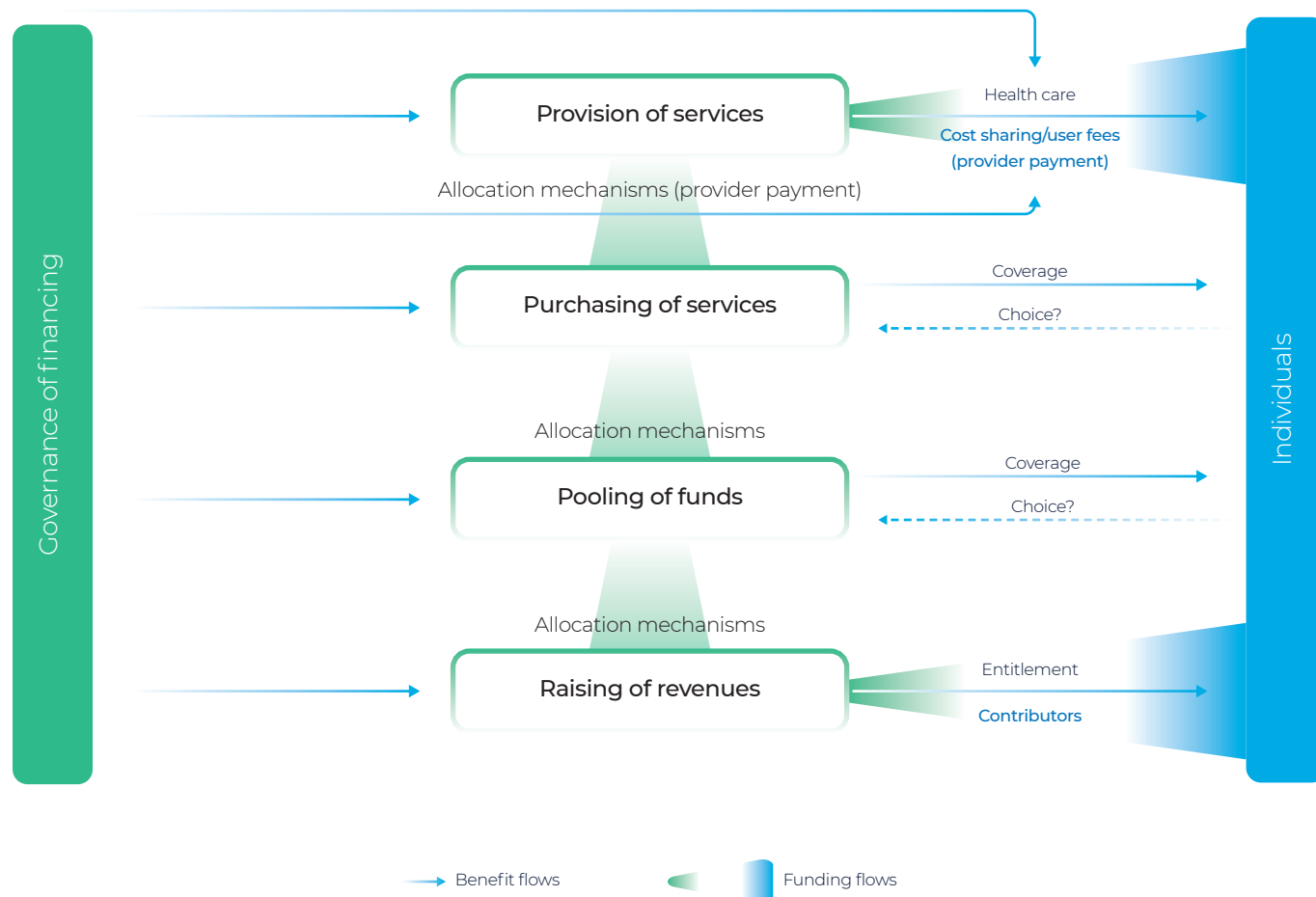
### 3.5.2 **ENABLER 2:** LEVERAGED FINANCING

Effective implementation of cancer programmes and services, including childhood cancer, requires a sustainable financing mechanism. Public financing of cancer programmes leads to a reduction in inequity in access to care, allowing for earlier diagnoses, higher compliance rates and reductions in morbidity and mortality, all while guaranteeing financial protection. This ensures that families of children with cancer do not suffer financial hardship, including catastrophic out-of-pocket expenditure.

Sustainable financing for childhood cancer should be aligned with general health system financing under the principles of UHC, framed by value for money. Childhood cancer services are known to be cost effective with significantly lower budget impact when compared with adult cancers (see Section 1.5).

For countries at all income levels, domestic resources should be utilized as the primary foundation of funding (Figure 41). A budget envelope from domestic resources should be identified for childhood cancer services, informed by costing of programmes. Currently, however, only 71% of LIC finance NCDs, predominantly through general government revenues, as compared to 100% of HIC (795). Data for childhood services are unavailable, however, this number is estimated to be lower when applied to childhood cancer services.

**Figure 41. Capabilities and shared care for financing and growth**



Various additional financing instruments may be utilized, including external and other extra-budgetary sources. Strategies for innovative and diverse cancer control financing can include multiparty strategic partnerships, pooling resources at regional or global levels or leveraging global health financing facilities, among others (197). These strategies have been employed with great success for childhood vaccines or treatment for malaria, tuberculosis or HIV, and also hold significant promise for childhood cancer. Catalytic funds from external sources could be leveraged to demonstrate the ability to scale up childhood cancer capacity, but would ideally transition to governmental funds. This strategy may be most relevant in LIC.

Foreign aid can theoretically increase access to care and improve population outcomes. However, international funding also risks a reduction in national public funding, a lack of long-term sustainability, and poor governance resulting in spending that does not accord with priorities.

Additional data and documenting of best practices can inform more effective sustainable financing mechanisms of childhood cancer. Select case studies, including from China and Mexico, have shown that allocation of domestic resources for a limited set of childhood cancer interventions as a first phase can demonstrate success (see Box 9) and lead to further inclusion of additional programmes in subsequent budget planning cycles. These successes are also increasingly driving development agencies and donors towards strategic investments in childhood cancer that yield immediate and impactful results (Box 15).

### Box 15. Uzbekistan, leveraged financing: on funding and management for capacity-building

*Thanks to strong political will and international cooperation, Uzbekistan has been improving the oncology system response to a growing number of cancer patients and the need for high-quality diagnostic and treatment facilities. Through several state programmes and leveraged financing from international development institutions, the country's health system has been strengthened, particularly in areas of perinatal care and primary health care. The same approach was implemented to achieve the Global Initiative for Childhood Cancer survival target of 60% by 2030. In 2018–2019, broad technical assistance was received from regional cooperation through the EurADO initiative and the WHO European Region. In 2020, with support from partners from the Republic of Korea, a modern children's hospital was opened in Tashkent, with 20 of 280 beds reserved for haemato-oncological patients.*

*Uzbekistan plans to invest an additional \$US 121 million (\$US 76 million loan) during 2021–2025 by focusing primarily on cancer prevention, early detection and accelerated introduction of high-tech methods to improve cancer diagnosis and treatment, including strengthening childhood cancer care facilities across the country.*

Sandra Luna-Fineman, Children's Hospital, Colorado, USA



### 3.5.3 **ENABLER 3:** LINKED GOVERNANCE

Developing an effective governance structure is critical to effective implementation of childhood cancer services within the broader health system. Robust governance requires strong political will.

Core leadership and governance actions must be developed, linked to national strategies (198,199):

- Identifying gaps and formulating needs.
- Collaboration and coalition-building across sectors and with external partners (see also Enabler: Advocacy, Section 3.5.1).
- Generating data to inform ongoing decision-making (see Pillar 4, Section 3.4).
- Formulating policy and strategic plans.
- Putting in place levers or tools for implementing policy, including: design of health system organizational structures; legislations and regulation; standard-setting; incentives; enforcement and sanctions; and accreditation (see Section 4 and Pillar 1, Section 3.1).
- Ensuring accountability by putting in place: governance structures, rules and processes for health sector organizations; mechanisms for independent oversight, among others; and openness to scrutiny by political representatives and civil society (see Section 3.5.1).
- Evaluation, feedback and refinement of policies.

**Formulating national cancer control policies:** Strong national policies for cancer control define the agenda for improving access to care and must be informed by robust national data (153). The objectives and process of cancer control formulation should contain core elements and must be comprehensive, coherent and consistent (124).

Core elements of a cancer control formulation:

- People-centred, carefully prepared through a participatory process.
- Goal-orientated, realistic.
- Based on context-specific childhood cancer data that are transparently presented.
- Defines population and target and goals and objectives.
- Establishes priorities and considers the gradual implementation of a few, affordable, cost-effective, evidence-based and priority interventions.
- Integrates strategies with other programmes (e.g. UHC).
- Defines available financing mechanisms and resources.
- Sets out a monitoring and evaluation framework.
- Engages stakeholders, including private sector and civil society and advocacy organizations.



Rodrigo Caytán, AYUVI/Unidad Nacional de Oncología Pediátrica, Guatemala

National health plans, such as national cancer control plans, should define priority childhood cancer programmes to be implemented that are coherent with other national policies (Box 16). Interventions are required across the cancer continuum from early detection through treatment to palliative and survivorship care. Interventions must be consistent with evidence-based best practices.

The inclusion of childhood cancer in national plans requires acknowledgement of its specificities. These specificities apply to nearly all aspects of childhood cancer, including tumour biology, types of services required and which stakeholders to engage (see Section 1).

Effective inclusion of childhood cancer requires a stepwise approach beginning with data for decision-making, priority setting, formulation of the plan, financing, implementation, and monitoring for impact (Figure 42). Children with cancer, supported by multisectoral partners, should be at the centre of this process.

## Box 16. Characteristics and components of a cancer control plan

Elements	Policy examples
Information systems	Cancer as a reportable or notifiable disease, with burden and outcomes measures and quality control programmes.
Prevention	Limited relevance in childhood cancer but can include strategies applicable to children, such as hepatitis B vaccination to prevent liver cancer, HPV for cervical cancer prevention, HIV control and Kaposi sarcoma, Epstein-Barr virus (EBV) prevalence and childhood cancers.
Early detection	Strategies to improve time of symptom onset to treatment; training of primary care professionals.
Diagnosis and treatment	Supply chain management to improve access to medicines and technologies.
Palliative and supportive care	Training for primary care providers to prescribe oral morphine and comfort care.
Service delivery	Care pathway with navigation programme.
Governance	National focal point for cancer programme implementation.
Finance	Inclusion of childhood cancer in national benefits package.
Health workforce	Accreditation for occupations to improve optimization and skill mix.
Research	National research priorities identified and funding allocated.

**Figure 42. Process of cancer control planning, financing, implementing and monitoring**





### Coalition-building across sectors

Diverse, multisectoral engagement, including the private sector and civil society, strengthens governance in childhood cancer by incorporating stakeholder inputs and contributions to a shared objective. This should be done under the leadership of designated Ministry of Health directorates or committees.

Broad stakeholder mapping and engagement are assets that increase the effectiveness of an implementation network. Transparency and equity must be guiding principles for multisectoral dialogue to foster trust, and synergies should be optimized whenever possible. Accountability and ownership are key principles for stakeholder engagement.

### Generating data to inform decision-making

The use of national childhood cancer data should be used to set priorities and inform decision-making (see Pillar 4, Section 3.4).

### Levers or tools for implementing policy

Governance is strongest when operationalized with statutory, legal or regulatory force. Select legislative measures have been used to potentiate childhood cancer programmes. Customary legislation includes guaranteeing access to care as part of a UHC scheme (Mexico, the Philippines), maximum acceptable times between referral and treatment (Chile), parental social protection (Mexico, Peru), anti-discrimination protection for survivors (European Union) as well as advancing research and innovation (United States) (Box 17).

Ensuring effective, non-inhibitory regulatory measures also enable effective governance and strengthen childhood cancer programmes. Regulatory interventions that strengthen oversight of workforce services or cancer products promote quality.

### Ensuring accountability through defined governance structure: Steering Committee

While models of governance are highly context specific, guiding principles should include transparency, consistency, coherence, stability, participation, accountability, integrity and capacity (56). These principles guide the formation of institutional structures, lines of responsibility and accountability, and reporting mechanisms.

A national or regional authority for childhood cancer control should be designated and codified in related documents for child health and broader cancer control. A Steering Committee with dedicated clinical and non-clinical leaders who act as focal points, working with advocacy communities and civil society organizations, can help prioritize childhood cancer on the national agenda and thus accelerate progress in childhood care (136).

### Evaluation, feedback and refinement of policies

Monitoring, evaluation and review of childhood cancer policies are essential functions for implementation of priority health actions against stated objectives and desired results and should be organized through a single country-led platform (199). The value of evaluation yields accelerated progress, monitoring for inequalities and greater accountability.



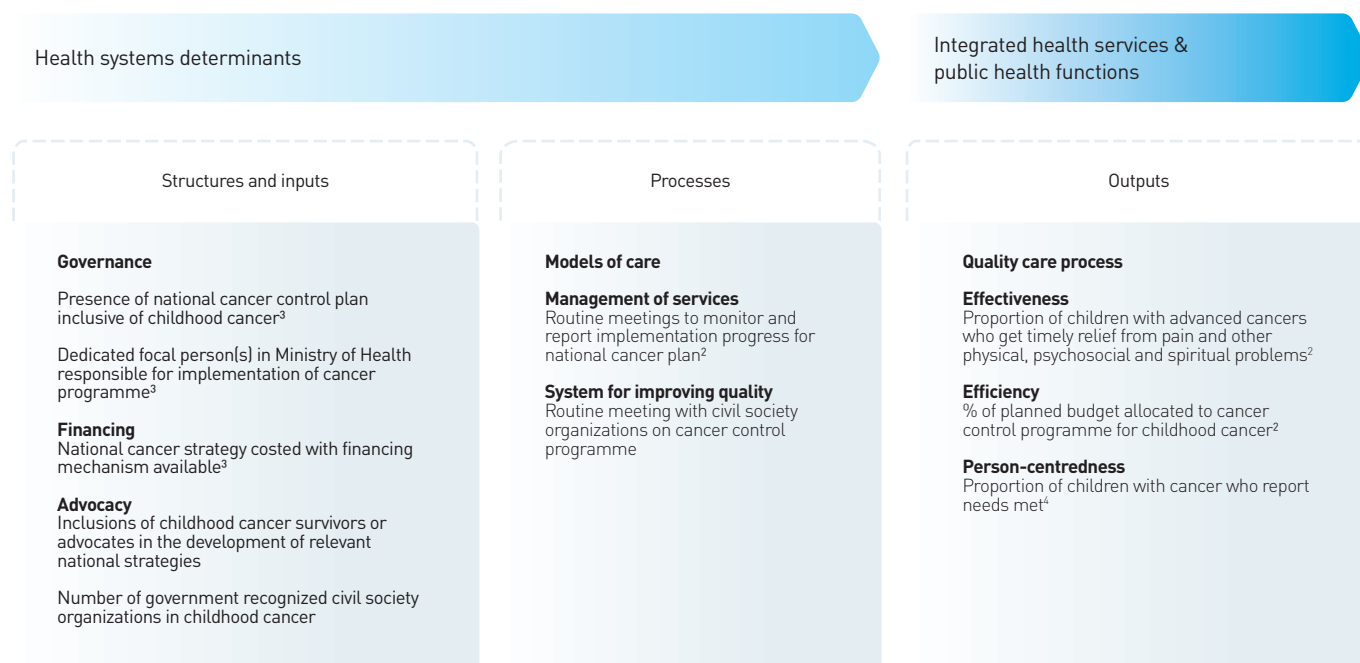
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## SAMPLE METRICS

Figure 43 outlines the sample indicators for enablers.

**Figure 43. Metrics for enablers**



Sources: 1. WHO 2006 (124); 2. WHO Regional Office for the Eastern Mediterranean 2017 (125); 3. WHO 2021 (126); 4. WHO 2014 (127); 5. Vasquez et al. 2021 (52).

### Box 17. Connecting political will to legislative action

Peru was designated as a focus country to participate in the Global Initiative for Childhood Cancer in June 2019, aligning with the Initiative's target, whereby a general goal of reducing morbidity and mortality from cancer in children under 18 years of age was set. To achieve this goal, three main lines of action were outlined: improve early detection; implement information systems for children and adolescents; and improve the quality of childhood cancer care. Acceleration of the implementation of the **CureAll** framework was possible through the development of an appropriate governance structure and coordinated country-level actions based on capacity-building and teamwork. Political will was transformed into legislation by the creation of the National Childhood Cancer Law in September 2020. This law allowed health coverage for the treatment of childhood

cancers, work licenses for the parents of children with cancer and the creation of a National Childhood Cancer Programme.

Political will also catalyses broad multisectoral engagement and strategic community alignment towards a shared goal. For example, in the United States, Congress passed the 21st Century Cures Act (Cancer Moonshot), with three goals as an effort to accelerate progress in cancer research in 2016: accelerate scientific discovery in cancer; foster greater collaboration; and improve data sharing. Authorizing US\$ 1.8 billion in funding over seven years, childhood cancer initiatives were created: Pediatric Immunotherapy Discovery and Development Network, Intensify Research on the Major Drivers of Childhood Cancer, and MyPart: Pediatric and Adult Rare Tumour Network.



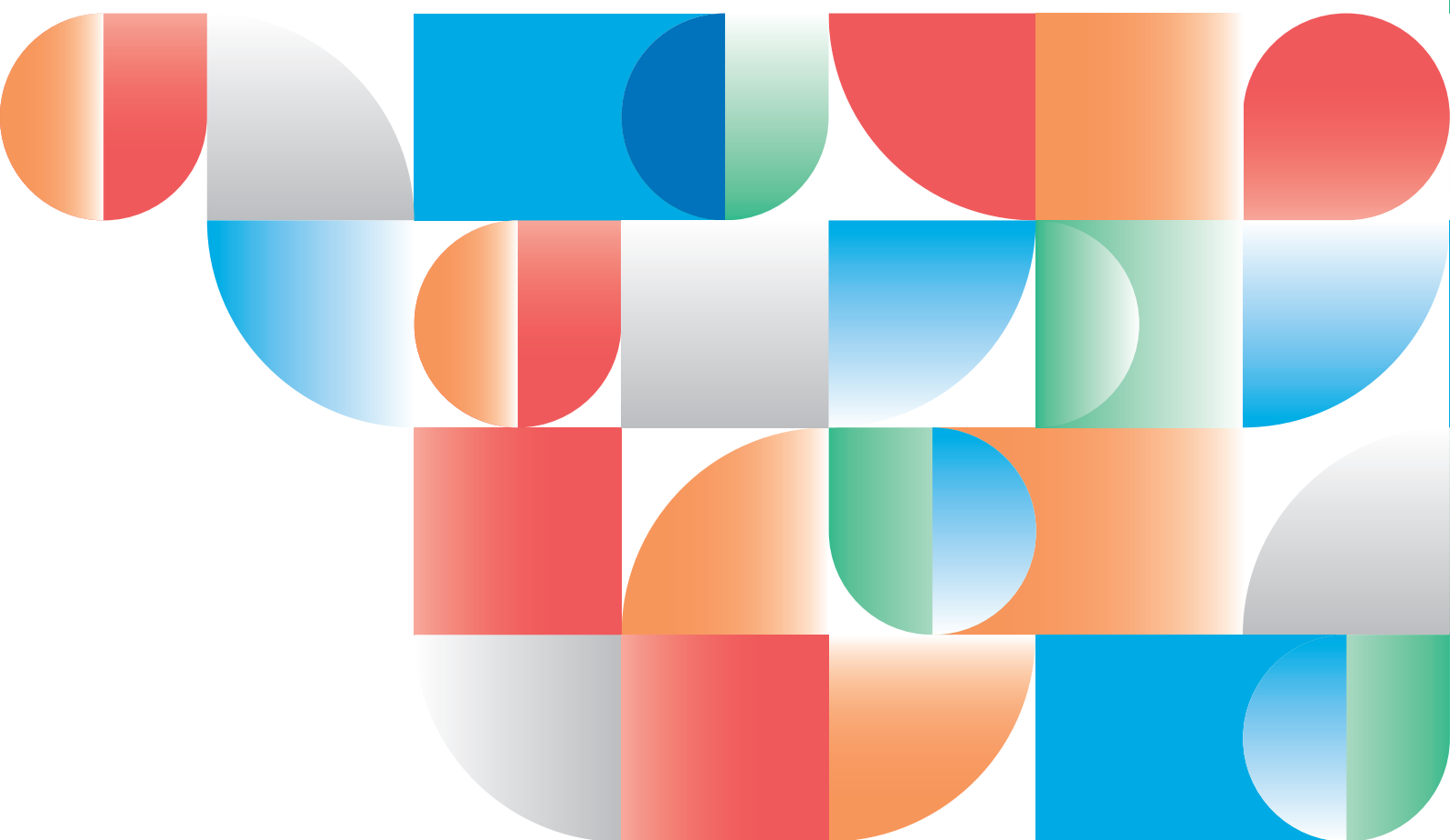
You never know how strong you are until being strong is the only option you have. Don't give up.

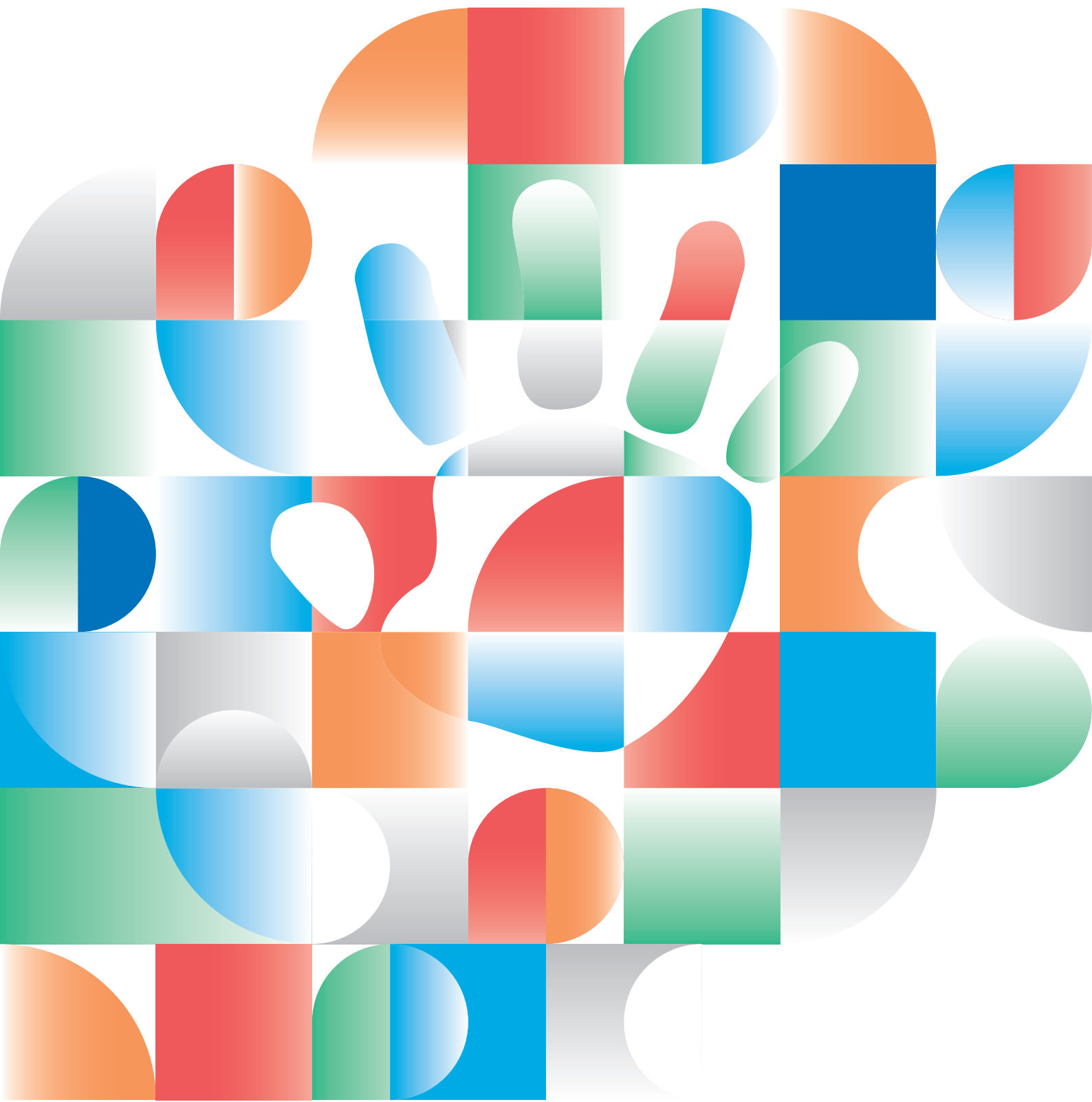
— Rama

Survivor of acute lymphoblastic leukaemia

## Section 4.

# Approach to implementation







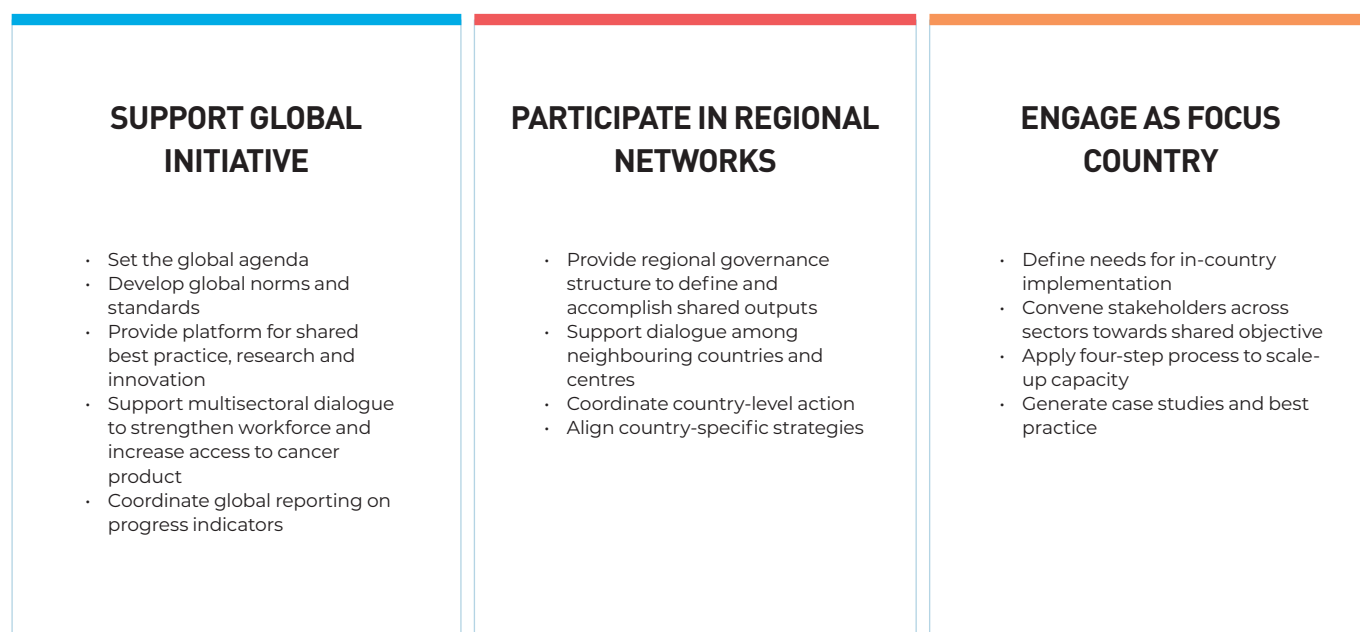
## 4.1 ACCELERATING IMPACT IN COUNTRIES AND REGIONS

The **CureAll** technical package is a framework for implementing key programmes at the national or subregional level with the recognition that the specific strategic approach will depend on a particular country's context.

Governmental authorities, WHO offices and partners all serve distinct and critical functions in the effective implementation of the Initiative

(Figure 44), linked to a robust implementation network, including academic partners, civil society and other non-state actors. The global platform for the Initiative is to provide operational or action steps for all countries according to each pillar and enabler, achieving a measurable impact and improving childhood cancer outcomes.

**Figure 44. Engagement opportunities**



Source: WHO 2020 (7).

At the regional level, outputs include: (i) developing and sustaining an appropriate governance structure to define and accomplish shared objectives and outputs; (ii) supporting dialogue among neighbouring countries regarding regional centres for training, clinical or logistics needs such as combined medication procurement; (iii) coordinating country-level action; and (iv) aligning country-specific strategies with regional priorities. This will be achieved by sharing information, experience and tools, including through a Community of Practice hosted by the WHO: Knowledge Action Portal (KAP) (Box 18).

At the country level, achieving the Initiative's targets requires strong multisectoral partnerships, building on successful implementation networks that already exist in many settings. Country-led implementation catalyses and mobilizes additional stakeholders and resources, resulting in new capacities benefiting the broader health system.

Country capacity can be developed by becoming formally designated as a "focus country" that carries with it a formal

endorsement from the Ministry of Health and unlocks a standard pathway of country support and engagement by WHO and Initiative partners. Countries can still build childhood cancer capacities through directed projects in childhood cancer control with WHO and/or partners or by strengthening cancer care more broadly with the recognition that secondary benefits in childhood cancer can be expected and monitored.

Countries can define their needs (using KAP at the national and facility level) to evaluate their current health system capacity related to childhood cancer care. As the initial assessment occurs, countries will prepare the goals and outcomes measures (indicators or other) to measure progress. They can either implement the entire four pillars and three enablers or focus on segments.

A menu of core projects can be considered, aligned with the pillars and enablers and as part of the strategies for **CureAll** implementation. This means that all stakeholders across sectors must contribute to attain the best possible outcomes through programme development, implementation, monitoring and evaluation (Figure 45).

## Box 18. WHO Knowledge Action Portal

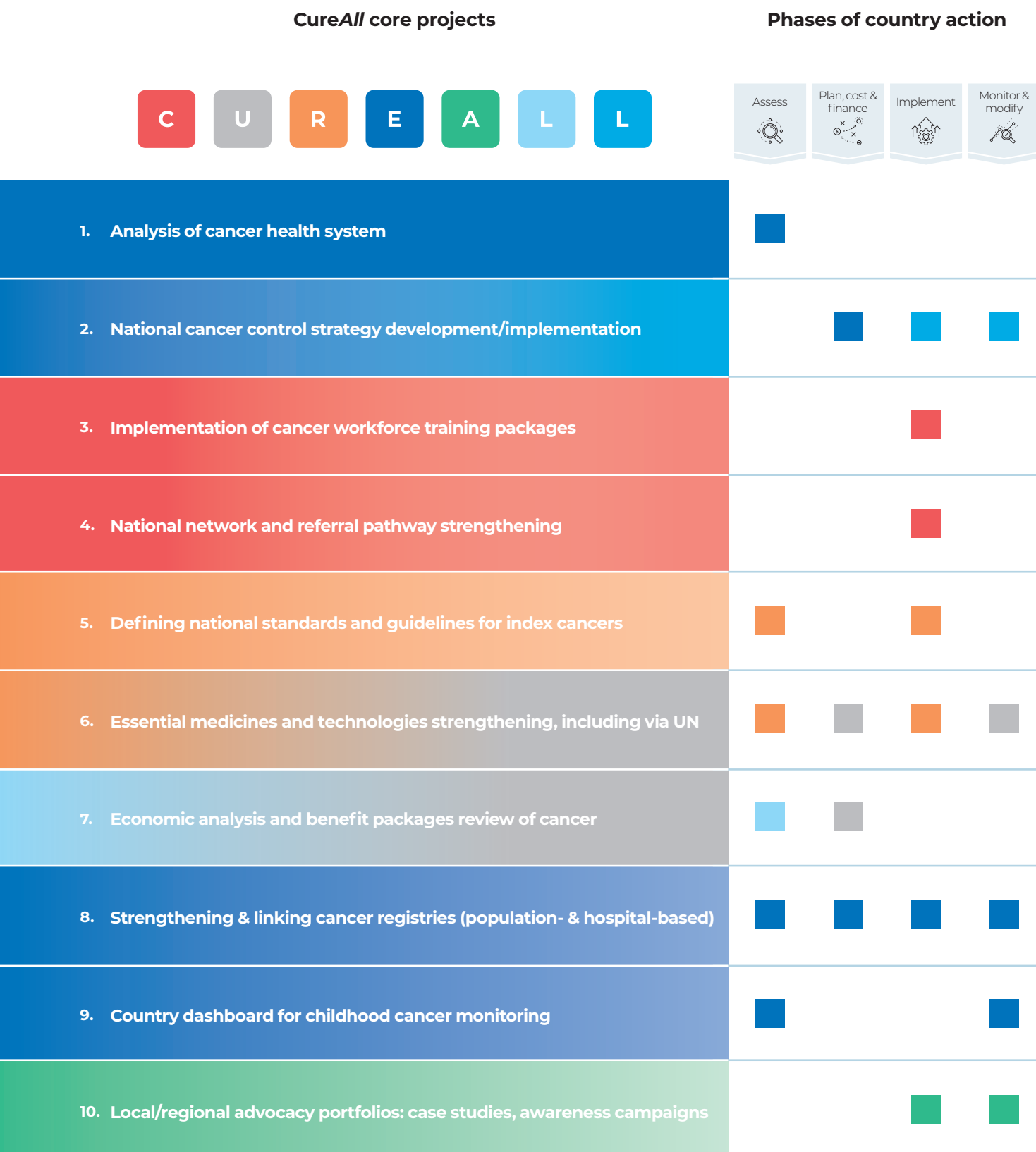
*The WHO Knowledge Action Portal (KAP) (<https://www.knowledge-action-portal.com/>) is a web-based portal that provides a guided environment for Ministry of Health representatives, sectors (e.g. national public and private, education, commerce), medical disciplines (e.g. medical, nursing, pharmacy) and partners (academic, nongovernmental organization, community) for three purposes that support the implementation of the Global Initiative for Childhood Cancer. First, KAP offers details on key partners within national and regional networks through an active directory of more than 100 organizations supporting the Initiative. This creates an active network able and willing to collaborate towards shared ends defined by ministries of health. Second, KAP provides educational tools, implementation experience and evidence-based strategies that can be shared. Finally, KAP allows for a fast and controlled growth and sharing of successes through the development of a QI collaborative (<https://www.knowledge-action-portal.com/>).*



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Figure 45. Core projects and intersection with pillars and enablers



UN: United Nations

Source: WHO 2020 (7).

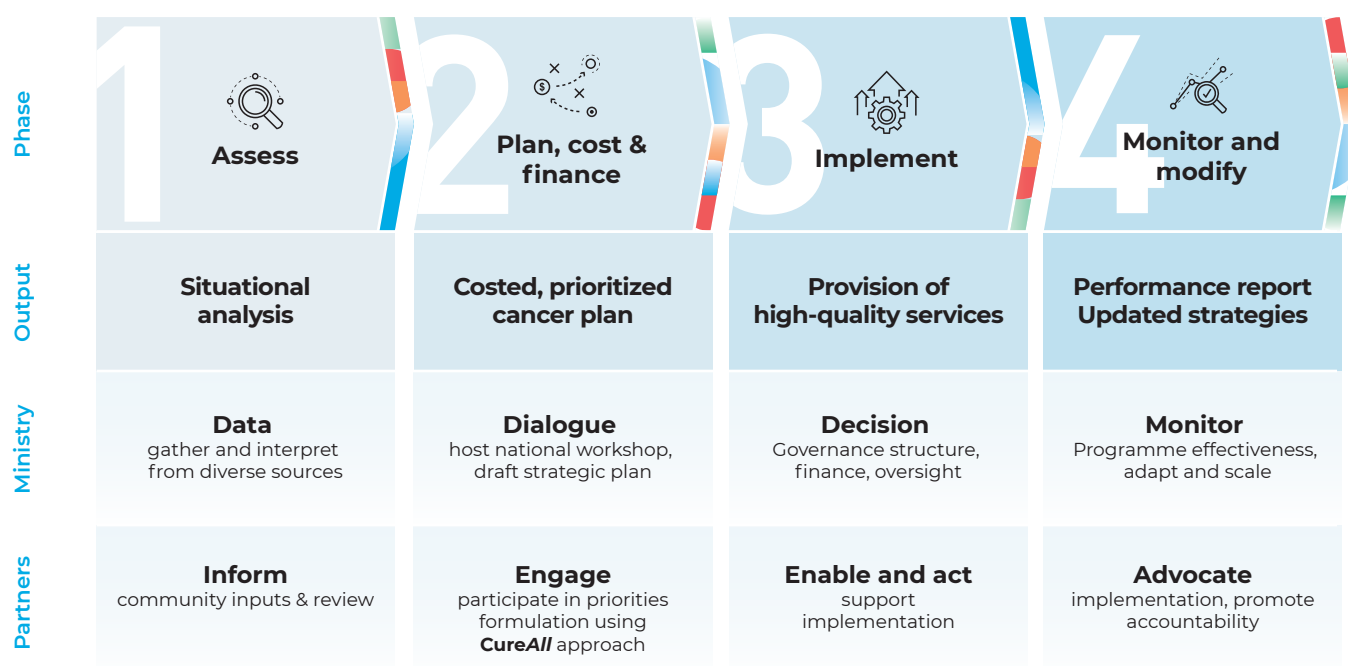


## 4.2 IMPLEMENTATION APPROACH

Tailored for each country's context, the **CureAll** technical package provides a rubric for governments proceeding through four

phases of country action towards successful implementation (Figure 46) (193).

**Figure 46. Sample country actions for the Global Initiative for Childhood Cancer**



Source: WHO 2020 (7).

### ASSESS

The first critical step is assessing the current situation of childhood cancer services, using the OneHealth Tool for cancer, a specialized tool from WHO and the International Agency for Research on Cancer, created for the Initiative (200). Assessments are conducted at the national and facility levels and coupled with site visits as appropriate. This situational analysis generates a country profile summarizing

the national childhood cancer landscape and aids government stakeholders in identifying high priority interventions across the health system (Figure 47). Additional data inputs needed in the initial assessment relate to mapping of existing stakeholders and activities. WHO, working with other United Nations agencies and implementation partners, can provide and coordinate support to conduct the situational analysis. This will provide Member States with a Childhood Cancer Country Profile that will serve as a baseline status from which to measure progress.

**Figure 47.** Sample Childhood Cancer Country Profile



## PLAN, COST AND FINANCE: PRIORITIZATION AND POLICY DIALOGUES

The second implementation step is to convene a strategic national workshop or consultation, attended by key leaders and implementing partners, to formulate a prioritized action plan and operational approach. Country-identified priorities are defined, prioritized and costed. The **CureAll** approach can be used to define priority actions. A group of implementing partners are identified through multiple dialogue and can be invited to contribute to the policy dialogue and anticipate opportunities for strengthening collaboration for capacity-building, service delivery and/or financing. Parallel to this, the other regional Member States implementing **CureAll** are contacted to share experience and positive innovative

Expected outputs may include stakeholder feedback on the outputs of the initial situational analysis, policy dialogues to support integration and alignment of childhood cancer within national planning, and a costed strategic plan with prioritized interventions for implementation (Figure 48).

## IMPLEMENT

There are four stages supporting effective implementation of cancer programmes: adoption; preparation; implementation; and scale-up (6). Once the national strategic plan or policy has been adopted, preparation for implementation must start by establishing concrete tasks followed by engaging and assigning relevant agencies, which may include government agencies, facility managers, partnering organizations and civil society.

The objective is to build “a learning childhood cancer care system” in which the requisite capacities and capabilities for scale-up can be estimated, recognizing the impact of changes in wider health care. Such decisions are not based on technical criteria only; in many cases, political values and the characteristics of participating organizations also play a role. Regional and local governance structures can support the alliance between community-based support activities and government policies. The country can also consult partners through the WHO Knowledge Action Portal (KAP) website on ideas, tools, educational strategies and specific guidance documents on diagnosis, therapy and outcomes measures. These are also linked to quality assurance during the process, allowing for modification and improvement of existing childhood cancer programmes.

## MONITOR AND MODIFY

Robust information systems generating high-quality and timely data are needed for all four stages of country action. Such data enable planning and decision-making, safeguard the quality of cancer management services and improve cancer outcomes. Surveillance and information systems must be available at both the national and facility levels to monitor and evaluate the impact of interventions and to scale up services. Monitoring is the systematic and continuous process of observing, collecting and storing data related to implementation of a core project or programme; it is linked to evaluation of a periodic analysis of activities to determine their effectiveness (56), thus how specific outputs are chosen to support the outcomes measures.

Inherent to the **CureAll** framework is a relevant core set of defined indicators allowing stakeholders to monitor and respond to identified programme needs by focusing on QI linked to research and innovation. Countries select a group of outcomes measures (indicators) at the outset and in line with objectives of the strategic plan or programme.

QI is an approach to develop, monitor and advance service systems and processes through the routine use of health and programme data (193,202). QI interventions are a change process that should be implemented in "...systems, services or providers for the purpose of increasing the likelihood of optimal clinical quality of care measured by positive health outcomes for individuals and population" (203). QI projects can be developed through collaborative approaches allowing stakeholders to work together to identify what should be done about a particular challenge, how it should be done and intended outcomes (that is, programme theory).



## 4.3 THEORIES OF CHANGE IN CHILDHOOD CANCER

Theories of change (ToC) are models that describe how an initiative, such as a policy, strategy or programme, contributes, through a sequence of events, to the intended result (204). They describe how, and under what conditions, interventions can bring long-term desired outcomes, and why a desired change is expected to happen in a particular context, making explicit the conditions needed and acknowledging the specific role of context. ToC can be used to design and measure the impact of public health programmes, and have been used by WHO to improve result-based programming (205,206).

The principles of ToC can be applied to the assess-plan-implement-monitor pathway used in this Initiative and to inform perspectives before initiating the **CureAll** pathway activities. In practice, this can be done by:

- convening a workshop with key stakeholders, including children with cancer and others who are living with cancer to construct a ToC for the **CureAll** implementation; an independent facilitator with experience in ToC can be considered;
- reflecting on the earlier outcomes that need to occur for the interventions to have an impact and the mechanisms by which those interventions might work;

- identifying the needed conditions for results to be obtained, and making sense of the context in which the interventions will be implemented using input from children with cancer; and
- defining indicators that will allow monitoring of intermediate and final outcomes of the implementation.

At the centre of ToC are children who live with cancer and their families who should be fully empowered to choose, to know, to thrive and to demand (207). Powers to choose child-focused approaches to care, removal of legal barriers, community-led services, protection of civic spaces to give voice to children with cancer. Powers to know and to be educated on available services. Powers to thrive for a full lifetime among children diagnosed with cancer and to overcome discriminatory practices. And, power to demand policies responding to the needs of children with cancer and remove barriers for marginalized populations.

By focusing on children with cancer and using a consultative process, ToC helps to articulate the change process within complex interventions, reflecting on how programmes can result in change. It must be an ongoing and iterative process which requires regular review (206).

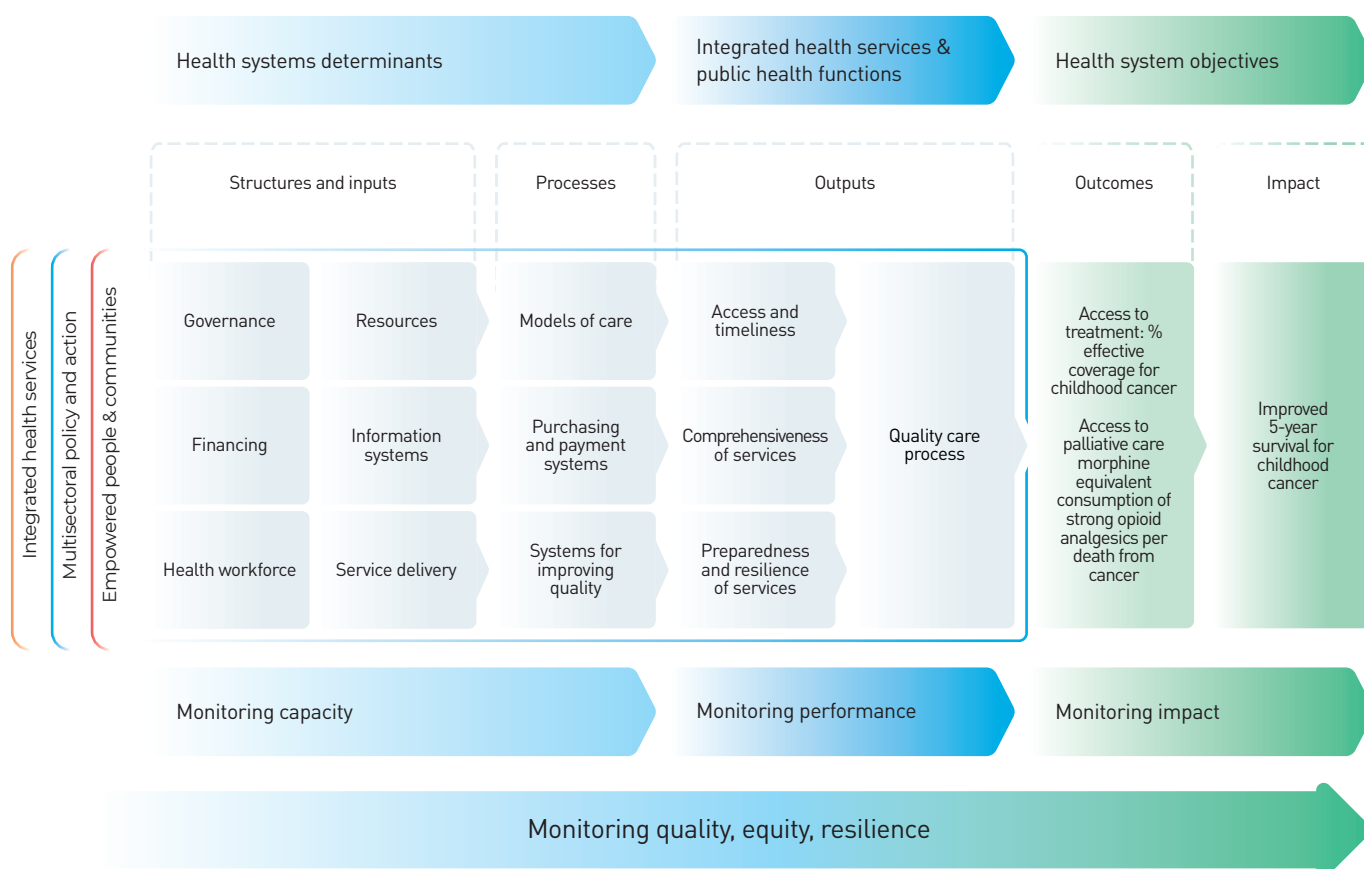


## 4.4 RESULTS CHAIN FOR CureAll TECHNICAL PACKAGE

The **CureAll** logic model is developed to facilitate evaluation of programmes and to guide research and evaluation projects. Logic models can be used to outline assumptions about the chains of process or activities occurring during implementation. Logic models can be used in evaluations studies to structure data collection and facilitate stakeholder engagement, producing context-specific research knowledge (208).

As the **CureAll** is implemented, a specific group of outcomes measures can be linked to structure, process and output indicators and organized according to the **CureAll** framework (see Sections 3.1, 3.2, 3.3, 3.4) or to the 10 priority actions (see Section 4.1) (Figure 48). These Indicators can produce a results framework, tailored to a country context and that utilizes existing information systems and reporting platforms.

**Figure 48. Results chain linked to health system objectives and the outcomes and impact associated with the Initiative**







## 4.5 TOOLKIT FOR IMPLEMENTING CureAll

To support implementation of the **CureAll** approach, additional technical products will be included as part of a broader package of goods to support country-level planning, implementation and/or monitoring (Figure 49), which include:

- 1. Tool to support priority setting, budgeting and health system planning:** Building on the WHO OneHealth Tool that is used by governments in national health planning, a specific module on cancer is available to help national decision-makers understand the impact, cost and feasibility of over 200 different cancer interventions for at least six child and eight adult cancers. Different scale-up scenarios can be explored according to current country health-system capacity, fiscal space and identified targets. This tool will also allow for a country-specific investment case.
- 2. Tool to facilitate national dialogue in health workforce planning:** Utilizing the WHO Global strategy on human resources for health: Workforce 2030 (59) framework, a customizable tool has been developed to assist stakeholders in understanding the unmet need in the cancer workforce, and to identify optimization strategies to address workforce shortages using a labour market approach.
- 3. WHO guidance for six index childhood cancers and supportive care:** Connecting WHO guidance materials, including for priority medical devices and the WHO EDL, the WHO EML, as well as cross-cutting resources for supportive care, new resources will be developed to inform management across various care settings.
- 4. Access to cancer health products programme:** WHO support for access to medicines and technologies span the pharmaceutical value chain to meet the needs of specific Member States.
- 5. Define global research priorities:** Aligning with the approach used by the WHO Global Observatory on Health Research and Development (R&D), a global framework for research priorities will be established. Areas for cross-sectional research (e.g. antimicrobial resistance) will also be identified.
- 6. Logic model and strengthening of cancer registries:** Guidance on the specificities of developing cancer registries for childhood cancers will be produced. Additionally, the monitoring framework for the Initiative will be released, providing guidance on defined indicators and facilitating reporting at the regional and/or global levels.

**Figure 49. Toolkit with sample elements to support implementation of CureAll across the phases of country action**

Phases of country action	Areas of support available	Sample key country actions
Assess	Assessment tools	<ul style="list-style-type: none"> <li>Stakeholder map</li> <li>National and facility rapid assessment tool</li> <li>Country profile</li> </ul>
Plan, cost & finance	Prioritization & policy dialogues	<ul style="list-style-type: none"> <li>National workshop templates</li> <li>Tool to support priority setting, budgeting and health system planning</li> <li>Sample inputs for country-level investment case for childhood cancer</li> <li>Workforce planning tool</li> </ul>
Implement	Programme implementation support	<ul style="list-style-type: none"> <li>WHO guidance for management and supportive care for six index childhood cancers</li> <li>Programme on access to cancer medicines and technologies</li> <li>Sample strategies for workforce scale-up</li> </ul>
Monitor & modify	Programme monitoring & improvement support	<ul style="list-style-type: none"> <li>Core dataset for cancer registries and programme monitoring</li> <li>Framework for research priorities</li> </ul>

Source: WHO 2020 (1).

Together, this toolkit will provide an operational framework and implementation framework necessary to ensure that delivered services are integrated, efficient and of high quality (Figure 50).

Figure 50. Toolkit with sample elements to support implementation across the CureAll pillars

Pillars	Sample tools /templates	Sample resources	Sample cross-cutting enablers		
			Advocacy	Leveraged financing	Linked policies/governance
<b>Centers of excellence and care networks with sufficient competent workforce</b>	Assessment tool (national and facility level), health workforce planning tool	Sample strategies for workforce scale-up			
<b>Universal health coverage with benefit packages and organizational models for quality services</b>	Tool to support priority setting, budgeting and health system planning	Sample inputs for country-level investment case for childhood cancer	<b>Country resources</b> <ul style="list-style-type: none"> <li>Country case studies</li> <li>Country profiles</li> <li>Workshop templates (concept note, agenda, list of participants)</li> <li>Menu of sample interventions post-workshop</li> </ul>		
<b>Regimens for management with context-appropriate guidance, essential technologies and medicines</b>	WHO guidance for management and supportive care for six index childhood cancers	Programme on access to cancer medicines and technologies <ul style="list-style-type: none"> <li>WHO Essential Medicines List</li> <li>WHO Essential Diagnostics List</li> <li>WHO Priority Medical Devices</li> </ul>	<b>Regional/global resources</b> <ul style="list-style-type: none"> <li>Stakeholder map inputs</li> <li>Infographics</li> <li>Fact sheet(s) on childhood cancer</li> <li>Regional case studies</li> <li>Highlights on how childhood cancer aligns with regional roadmap for control of cancer and/or NCDs</li> </ul>		
<b>Evaluation and monitoring with quality assurance and information systems</b>	Core dataset for cancer registries and programme monitoring	Framework for research priorities			



The only way out is  
through. Keep the  
fight strong  
and positive 🇵🇪

— Frida

Survivor of acute lymphoblastic leukaemia



**Section 5.**

# Conclusion



Prior to the mid-20th century, childhood cancer was a universally fatal disease. The global history of childhood cancer, since then, has had two threads. In one, childhood cancer received substantial investments to drive innovation and health system improvements. Progressive and substantive improvements in outcomes were achieved through increases in access to care, treatment quality and reductions in toxicity. Millions of children and their families benefited and broader social and economic benefits were achieved.

In the other thread, the vast majority of children in LMIC have seen minimal progress in access to care. Inequalities have been exacerbated within and between countries. Children with cancer suffered. Social cohesion disrupted.

These two threads are now changing and converging towards a new vision: that every child with cancer has access to the best available care, driven by innovation, and that no child should suffer unnecessarily. This vision is possible because of strong multisectoral commitments and established proof of concept. Recent progress has been achieved in countries that made strategic commitments and worked with partners and networks to improve access to care. Improving childhood cancer care is definitively possible.

The WHO Global Initiative for Childhood Cancer, working alongside other United Nations organizations and global partners and experts, provides a platform to deliver on the potential of improved childhood cancer programmes across the world, and the **CureAll** approach to implementation provides the pillars of actions and enablers as a roadmap.

This **CureAll** framework is part of a technical package that provides the key tools required to achieve progress through assessment of the current capacity, to formulate prioritized plans and to cost programmes, to implement through networks supported by the WHO Knowledge Action Portal and to measure progress using metrics as delineated in this framework document.

This is not an easy task, but a new history can be written where every child with cancer is given the best opportunity to cure and to have their suffering alleviated. Investment in children with cancer is feasible, necessary and justified – it saves lives and generates broader social gains advancing our societies into a more sustainable, equitable and promising future. Together, we can re-write the history of childhood cancer for the betterment of all children, everywhere in the world.





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# ANNEX: GICC WORKING GROUP MEMBERS (PHASE I)

The technical foundations for the **CureAll** framework document were guided by the members of the five GICC working groups. WHO acknowledges their valuable expertise and support.

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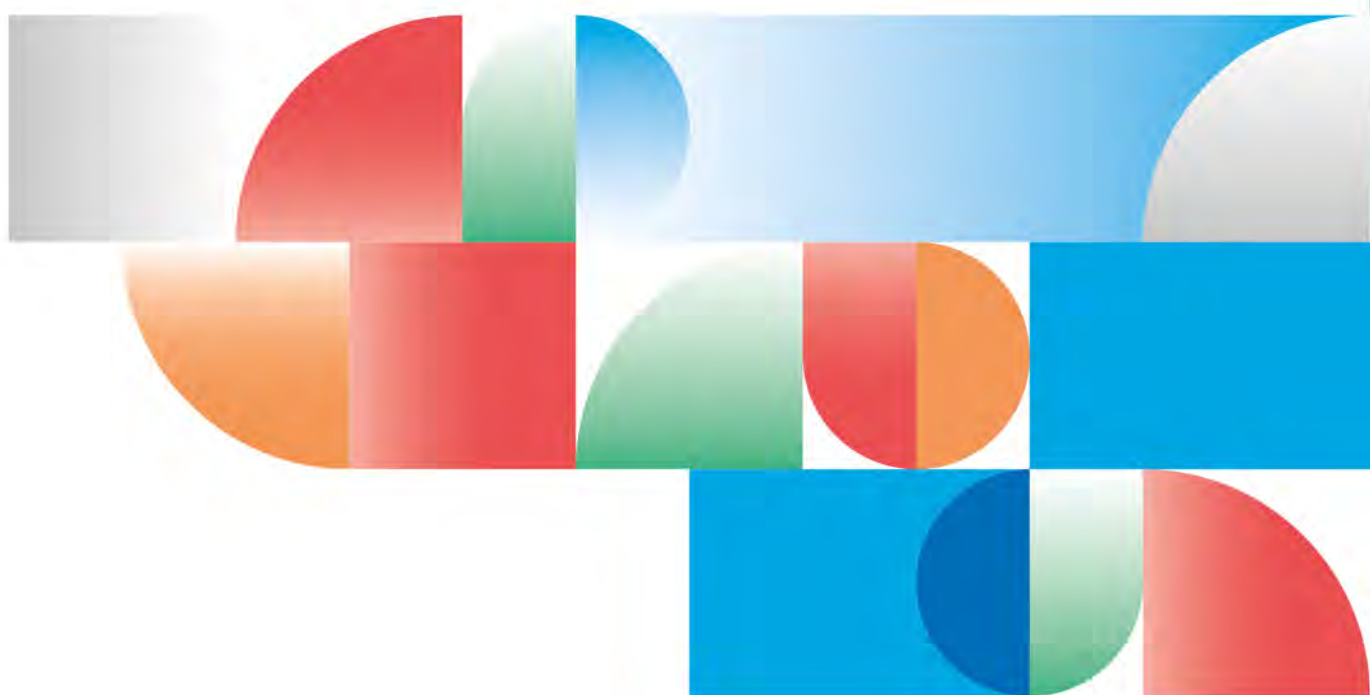
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