

Epidemiology of childhood cancer in Asia

Kayo Nakata,^{a,*} Yin Ting Cheung,^b Miho Kato,^{c,d} Giang Nguyen Huong,^{e,o} Chun Sing Lam,^b Tomohiro Matsuda,^f Eva Steliarova-Foucher,^g Kathy Pritchard-Jones,^h Kimikazu Matsumoto,^{d,i} Akihiro Yoneda,^{j,k} Hiroki Hori,^{d,l} Akira Nakagawara,^{d,m} and Chi-kong Li^{d,n}



^aCancer Control Center, Osaka International Cancer Institute, Osaka, Japan

^bSchool of Pharmacy Faculty of Medicine, Chinese University of Hong Kong, Hong Kong SAR, China

^cDepartment of Childhood Cancer Data Management, National Center for Child Health and Development, Tokyo, Japan

^dAsian Paediatric Haematology and Oncology Group

^eCancer Epidemiology Department, National Cancer Institute, National Cancer Hospital, Hanoi, Vietnam

^fNational Cancer Center Institute for Cancer Control, Tokyo, Japan

^gCancer Surveillance Branch, International Agency for Research on Cancer, Lyon, France

^hDevelopmental Biology and Cancer Research and Teaching Department, UCL Great Ormond Street Institute of Child Health, University College London, London, UK

ⁱChildren's Cancer Center, National Center for Child Health and Development, Tokyo, Japan

^jDivision of Surgery, Surgical Oncology, National Center for Child Health and Development, Tokyo, Japan

^kDivision of Pediatric Surgical Oncology, National Cancer Center Hospital, Tokyo, Japan

^lDepartment of Clinical Engineering Faculty of Medical Engineering, Suzuka University of Medical Science, Mie, Japan

^mSaga International Carbon Particle Beam Radiation Cancer Therapy Center, Saga HIMAT Foundation, Saga, Japan

ⁿDepartment of Paediatrics, Chinese University of Hong Kong, Hong Kong Children's Hospital, Hong Kong SAR, China

^oSchool of Preventive Medicine and Public Health, Hanoi Medical University

Summary

According to the 2022 estimates of the Global Cancer Observatory, 280,000 children (aged 0–19 years) are diagnosed with cancer worldwide, with more than 105,000 dying from it. Asia, with its population of 1.4 billion children, accounts for about half of these figures. In 2018, the World Health Organization launched the Global Initiative for Childhood Cancer (WHO GICC) with the goal of achieving at least 60% survival for children with cancer globally by 2030. In Asia, the 5-year net survival based on microsimulation model was estimated to be 39.6%, which was lower than the estimates reported for Europe (74.3%) and North America (83.0%). Incidence and survival data are essential to understanding the burden of childhood cancer, however, less than 5% of the childhood population is covered by population-based cancer registries providing comparable data on incidence in Asia. In this first paper of a Series on childhood cancer in Asia, we provide an overview of the available information on the childhood cancer incidence, mortality, survival and prevalence of survivors in Central, Southern, Eastern and Southeastern Asia. We highlight lack of comparable data, the challenges associated with data collection and propose strategies to improve childhood cancer data in Asia.

This is the first in a Series of three papers on childhood cancer in Asia (Paper 2 appears also in eClinicalMedicine and paper 3 appears in The Lancet Child and Adolescence Health).

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Keywords: Epidemiology; Childhood cancer; Asia; Incidence; Mortality; Survival; Population-based cancer registry

Introduction

Cancer in children is rare and is usually fatal if left untreated. According to the estimates of the Global

Cancer Observatory (<https://gco.iarc.fr/en>) for 2022, 275,713 children (aged 0–19 years) worldwide were diagnosed with cancer each year, and 105,345 died from

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Abbreviations: ALL, Acute lymphoblastic leukaemia; AML, Acute myeloid leukaemia; APHOG, Asian Paediatric Haematology and Oncology Group; ChildGICR, Targeting Childhood Cancer through the Global Initiative for Cancer Registry Development; CNS, Central nervous system; EMRO, Eastern Mediterranean Region; EURO, European region; GICC, Global Initiative for Childhood Cancer; HICs, High-income countries; IARC, International Agency for Research on Cancer; ICD-O-3, International classification of disease for oncology, 3rd edition; ICC-3, International classification of cancer in children (3rd edition); IICC, International Incidence of Childhood Cancer; LICs, Low-income countries; LMICs, Lower-middle-income countries; SEARO, South-East Asia region; SEER, Surveillance, Epidemiology, and End Results; SIOP, International Society of Paediatric Oncology; UK, United Kingdom; UMICs, Upper-middle-income countries; USA, United States of America; WHO, World Health Organization; WPRO, Western Pacific region

*Corresponding author. Cancer Control Center, Osaka International Cancer Institute, 3-1-69 Otemae, Chuo-ku, Osaka, 541-8567, Japan.

E-mail addresses: kayo.nakata@oici.jp, nakatakayoo@gmail.com (K. Nakata).

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cancer. Childhood cancer ranked sixth in the total cancer burden and ninth in the childhood disease burden, with 11.5 million disability-adjusted life years (DALYs) due to childhood cancer in 2017.¹ Asia, with its large population of 1.4 billion children, has the largest number of childhood cancer cases and deaths, accounting for about half of the global burden, followed by Africa and Latin America (Fig. 1).²

As in other regions, there are disparities in childhood cancer care among Asian countries. While more than 80% of childhood cancer patients in developed countries survive at least five years after diagnosis,^{3,4} it is believed that in some countries many cases are not diagnosed.⁵ For example, it is estimated that 9000 childhood cancers occur in Bangladesh annually, but only a quarter of this number are estimated to be

diagnosed and only 5% likely receive hospital treatment.⁶ In Pakistan, only about half of expected new patients are seen at the various treating facilities in the country.⁷ Lack of support system, such as health insurance schemes, coupled with long travel distances to reach specialised treatment centres, out-of-pocket costs required to cover diagnosis, treatment and transportation, inadequate referral networks and lack of education of health care providers and patients, are common culprits limiting access to diagnosis and treatment in many lower-income Asian countries.⁶⁻¹² With regard to treatment, there is a shortage of anti-cancer drugs, a lack of adapted protocols and clinical trials, and meagre educational opportunities for paediatric oncology specialists.¹¹ In India, less than 50% of the public tertiary hospitals had adequate stocks of

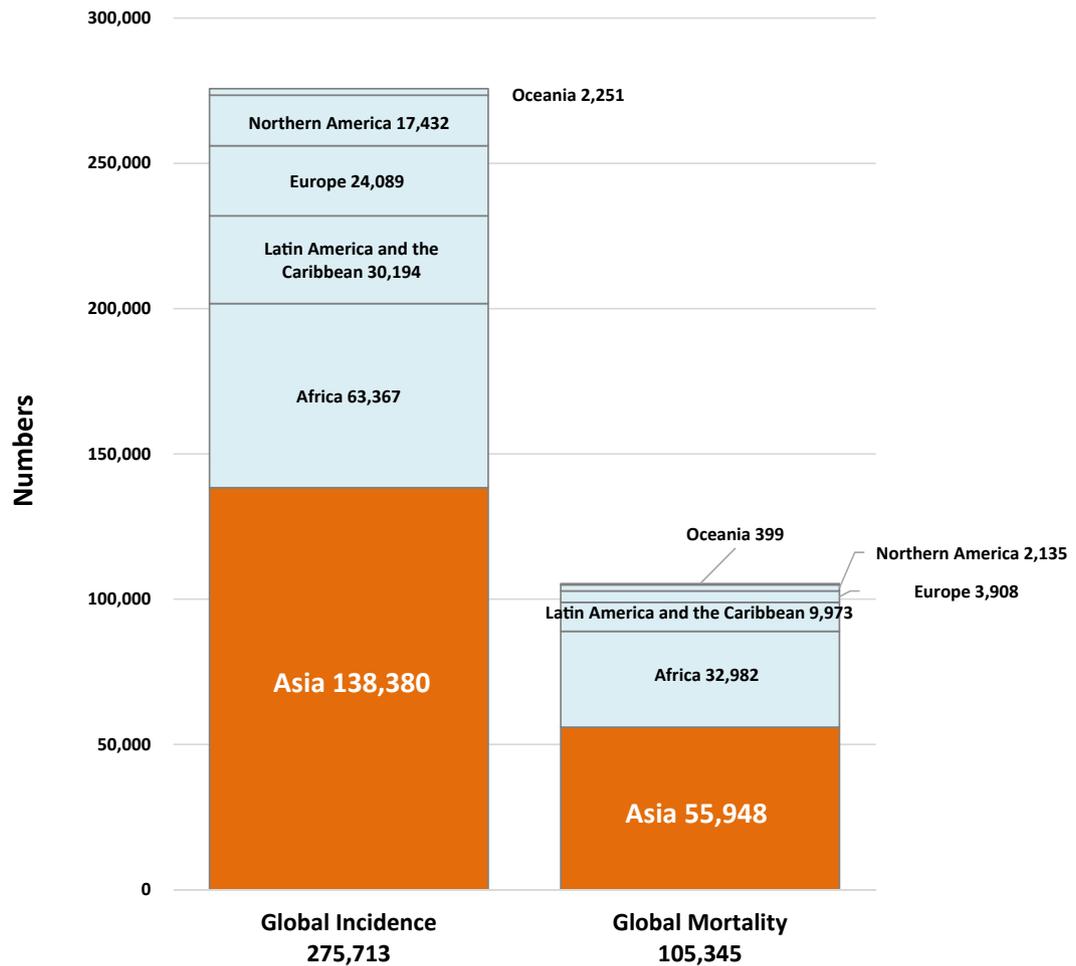


Fig. 1: Estimated number of new incidence and mortality in 2022, all cancers, both sexes, age 0–19 years. Source: Global Cancer Observatory, 2022. Asia includes Afghanistan, Azerbaijan, Bahrain, Bangladesh, Armenia, Bhutan, Brunei Darussalam, Myanmar, Cambodia, Sri Lanka, China, Georgia, Gaza Strip and West Bank, India, Indonesia, Iran (Islamic Republic of), Iraq, Israel, Japan, Kazakhstan, Jordan, Korea (Democratic People Republic of), Republic of Korea, Kuwait, Kyrgyzstan, Lao People’s Democratic Republic, Lebanon, Malaysia, Maldives, Mongolia, Oman, Nepal, Pakistan, Philippines, Timor-Leste, Qatar, Saudi Arabia, Singapore, Viet Nam, Syrian Arab Republic, Tajikistan, Thailand, United Arab Emirates, Türkiye, Turkmenistan, Uzbekistan, Yemen.²

antineoplastic drugs, targeted therapies products, supportive medicines, and palliative care options. Fewer than 10% of the tertiary level hospitals had a provision for training courses in paediatric oncology.¹³ Although the recent introduction of universal health coverage has reported significant reductions in treatment abandonment in Indonesia (from 14% to 6%)¹⁴ and China (from 54% to 6%),¹⁵ treatment refusal or abandonment remains an issue in these and other Asian countries. In addition to the financial hardship experienced by families, cultural or religious beliefs may also play a role in reduction of adherence to treatment.^{16–18}

The Global Initiative for Childhood Cancer by the World Health Organization (WHO GICC), launched in 2018, aims to improve overall childhood cancer survival to at least 60% by 2030.¹⁹ The Asia continental branch of the International Society of Paediatric Oncology (SIOP Asia) and Asian Paediatric Haematology and Oncology Group (APHOG) coordinate efforts to increase awareness, support better information on childhood cancer, affordable care, and local clinical research with the aim of improving outcomes for patients.

This Series on childhood cancer in Asia presents the current state of childhood cancer care and research in Asia. The first paper here examined the epidemiology of childhood cancer in Asia, while the second paper mapped the landscape of paediatric oncology clinical trials in Asia.²⁰ The third paper discussed the relevant hurdles and priorities for action to promote equitable and quality survivorship care for children with cancer in the region.²¹

Assessing childhood cancer incidence, survival, and mortality is crucial to understanding the current situation and identifying areas where additional efforts are needed. Monitoring these trends can also help to identify potential risk factors, allocate healthcare resources, and guide public health policies.²² Furthermore, understanding the disparities in outcomes across different populations will enable us to better address the inequity in cancer care and in the implementation of targeted interventions.²² In Europe, EURO CARE study revealed disparities in childhood cancer survival among 31 European countries using data from 80 population-based cancer registries, giving rise to important initiatives across Europe to reduce the gap.²³ In the United States, trends in survival for specific types of childhood cancer have been reported using data from Surveillance, Epidemiology, and End Results (SEER) program to evaluate childhood cancer care in the country.²² However, only a limited number of countries in Asia have population-based cancer registries, and there are few reports on the epidemiology of childhood cancer.

This review summarizes epidemiological data on the childhood cancer in Central, Southern, Eastern and Southeastern Asia, describing incidence, mortality, survival and prevalence of survivors where available.

We also discuss the challenges associated with data collection and initiatives aimed at addressing these challenges. We hope that this review will help understand the current situation of childhood cancer and childhood cancer registries in Asia and contribute to the development of cancer registries in each country.

Methods

Target countries

We defined the target countries in Asia as shown in [Supplementary Table S1](#). With the exception of Pakistan, countries in the Eastern Mediterranean Region (EMRO) defined by WHO (Afghanistan, Bahrain, Egypt, Iran, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Palestine, Oman, Qatar, Saudi Arabia, Sudan, Syria, Tunisia, United Arab Emirates, Yemen) were excluded as they are presented elsewhere.

Search strategy and selection criteria

To describe childhood cancer burden in the regions of Asia delimited in this study, we gathered information from several sources. We prioritised statistics provided by the International Agency for Research on Cancer (IARC), followed by other published sources for survival and prevalence of childhood cancer survivors which were unavailable from IARC. We conducted a narrative literature review. The search was completed on 30 September 2024.

- Incidence: We extracted observed age-standardised incidence from the International Incidence of Childhood Cancer study (IICC, <https://iicc.iarc.fr>).
- Mortality: We extracted age-standardised mortality estimates from the Global Cancer Observatory for 2022 (<https://gco.iarc.fr/en>). (For incidence and mortality, age-standardised rates are extracted in order to standardise differences in age composition between countries).
- Survival: As data on childhood cancer survival is sparse, we conducted narrative review. A comprehensive search of PubMed and Embase for relevant publications released in from 2000 to September 2024 was conducted to identify the reports of childhood cancer survival from the countries of interest. The search terms included keywords related to childhood cancer or specific cancer types, survival, and the names of Asian countries ([Supplementary Table S1](#)). Original research studies (population-based, cohort studies or trials carried out in multiple or single institutions) were included. Studies in which data for patients aged under 20 years were not provided were excluded. Additionally, secondary references from relevant papers were reviewed to identify articles not captured in the initial search. The primary focus was on 5-year survival, however survival for other

observation periods was also considered if no other survival estimates were available in a given region. We prioritised observed data using population-based cancer registry data as much as possible and avoid using model estimates, and we reported modelled estimates only when observational data were unavailable. The countries or regions were classified as low-income (LICs), lower-middle-income (LMICs), upper-middle-income (UMICs), and high-income countries (HICs) or regions according to the World Bank in 2022.²⁴

- Prevalence of childhood cancer survivors: As data on prevalence of childhood cancer survivors is also sparse, we conducted a comprehensive search of PubMed for relevant publications from 2000 to September 2024. The search terms included keywords related to prevalence of childhood cancer survivors and the names of Asian countries (Supplementary Table S1).

Childhood cancer incidence

Population-based cancer registries collect incident cases of cancer in a defined population and follow international standards. Tumour site, morphology, and behaviour are coded according to the International Classification of Diseases for Oncology, 3rd edition (ICD-O-3).²⁵ Cancers affecting children, in contrast to those occurring in adults, are often systemic in nature, and are classified into 12 main diagnostic groups using

the International Classification of Childhood Cancer (ICCC),²⁶ using the ICD-O-3²⁵ codes. The 2017 edition of the ICCC (ICCC-3-2017) provides for 115 detailed cancer categories.²⁷ The International Incidence of Childhood Cancer (IICC, <https://iicc.iarc.fr>) study, which is coordinated by the IARC, collates and disseminates comparable data from population-based cancer registries from countries around the world. From the first edition published in 1988²⁸ to the third edition (IICC-3) in 2017,²⁹ a total of 40 years of childhood cancer incidence data has been assembled for many areas. In IICC-3 study, the age-standardised incidence rate of childhood cancer (0–14 years) in 2001–2010 was 140.6 per million person years, with the incidence rates being higher in North America (157.6) and Europe (143.8–170.8), and lower in Asia (87.5–140.9) and Africa (56.3–110.9).²⁹ Currently, the IICC website (<https://iicc.iarc.fr/resultzts>) displays data from 82 countries and territories.³⁰ Fig. 2 shows the age-standardised incidence rates of main diagnostic groups in children aged 0–14 years in eight Asian countries, as well as the United States of America (USA) and the United Kingdom (UK) that were included in IICC-3. Childhood cancer incidence rates ranged from 135.9 in Republic of Korea to 75.6 in Pakistan. The most common cancers were leukaemia, lymphoma, central nervous system (CNS) tumours, among nine countries except for Japan. In Japan, the incidence of neuroblastoma was higher than lymphoma likely due to the organised screening carried out from

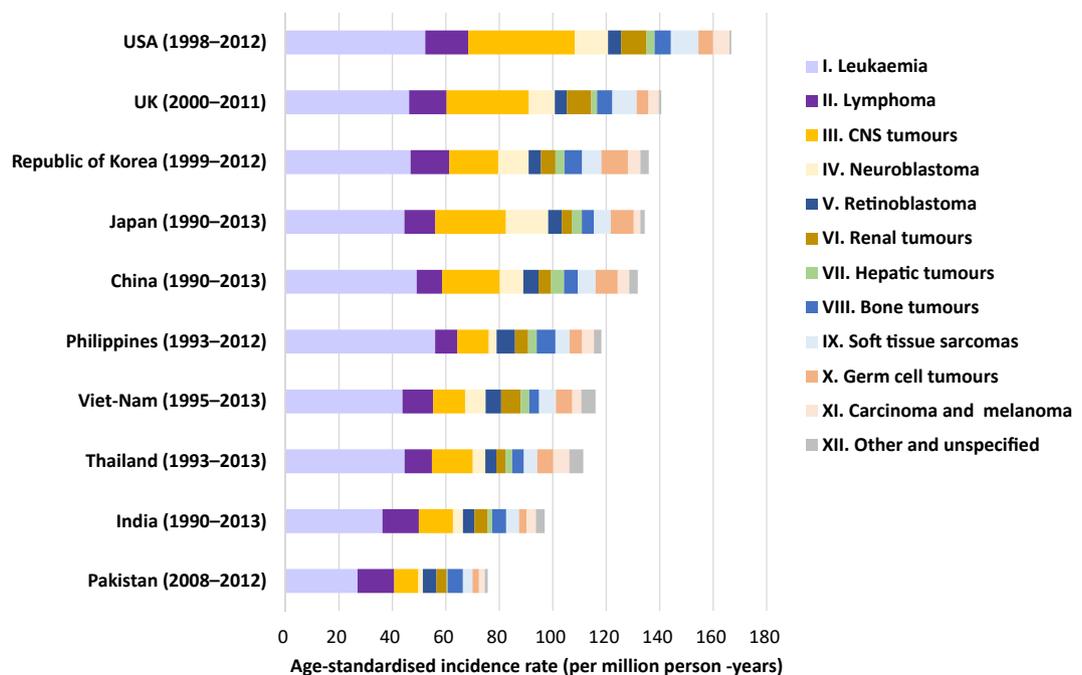


Fig. 2: Age-standardized incidence rates for main diagnostic group in eight Asian countries, USA and UK, age 0–14 years. Source: IICC-3.³⁰

1985 to 2003 and the residual clinical practice of neuroblastoma detection in later years.^{31,32} Looking at the incidence rates by country and main diagnostic group, incidence rates of germ cell tumour in East Asian countries (Republic of Korea = 9.9, Japan = 8.6, China = 8.3) were higher than those of USA (5.5) and UK (4.4) in IICC-3 (<https://iicc.iarc.fr>). Incidence rates of renal tumours were lower in Asian countries (Thailand = 3.4, Japan = 3.7, Pakistan = 3.8, China = 4.7, Philippines = 4.9, India = 5.0, Republic of Korea = 5.4, Vietnam = 7.3) than those of USA (9.5) and UK (9.1). By cancer subgroup, incidence rates of Hodgkin lymphoma were lower in East and Southeast Asian countries (Japan = 0.8, Republic of Korea = 1.1, Philippines = 1.1, China = 1.3, Thailand = 2.0) than those of USA (5.0), UK (5.9), and South Asian countries (Pakistan = 6.8, India = 5.7).³⁰ Incidence rates of Ewings tumour had similar trends (China = 0.6, Thailand = 0.8,

Philippines = 1.0, Japan = 1.1, Republic of Korea = 1.4 vs India = 2.1, USA = 2.2, UK = 2.3, Pakistan = 2.8).³⁰ These trends were consistent with previous reports.³³⁻³⁷ The high incidence rates may be due to genetic factors or environmental factors, advances in diagnostic technology and improvements in the accuracy of cancer registration. While the aetiology explaining the difference in the incidence of these cancer types for geographical regions has been partially reported in recent years,³⁷⁻⁴¹ much remains unknown and further investigation is required.

Childhood cancer mortality

Fig. 3 shows the age-standardized mortality rates of cancer in children aged 0–19 years in 2022 in 31 Asian countries as estimated by the Global Cancer Observatory.² Mortality data are the estimates based on data

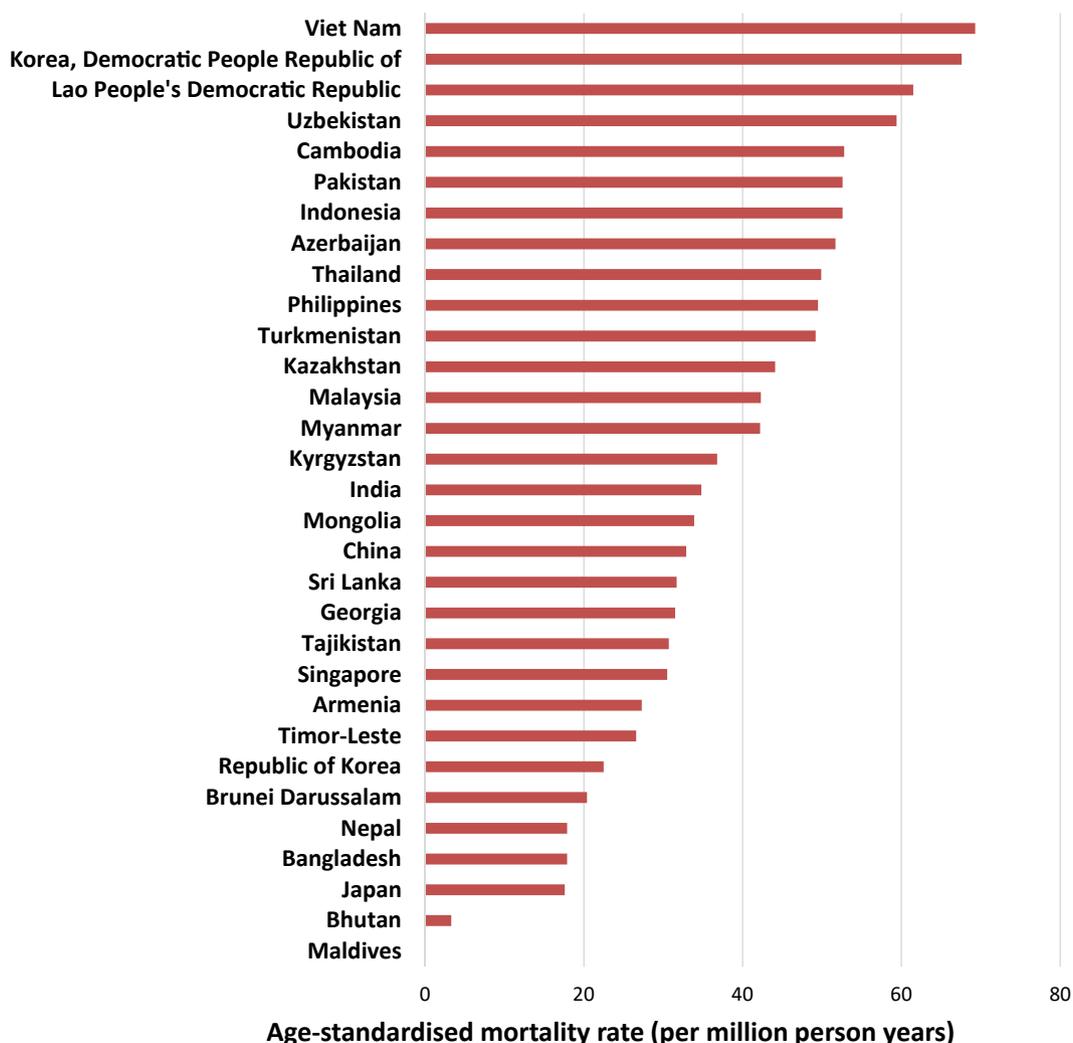


Fig. 3: Age-standardized mortality rates in 31 Asian countries, 2022, all cancers, both sexes, age 0–19 years. Source: Global Cancer Observatory 2022.²

provided by national mortality statistics and population data. In the absence of these sources, data provided by other sources (population-based cancer registries within the same or neighbouring country) are modelled.⁴² This means that the methodology of estimation differs by country and depends on the granularity and quality of data available. As many Asian countries do not provide cancer mortality, it was modelled and provided with a credibility measure.⁴² Childhood cancer mortality varied widely within Asia, ranging from 69.3 per million in Vietnam to 0.0 per million in Maldives. Mortality rates were low in HICs such as Singapore (30.5), Republic of Korea (22.5), Brunei Darussalam (20.4), and Japan (17.6), while high in LIC (Democratic People's Republic of Korea = 67.6) and LMICs (e.g. Vietnam = 69.3, Lao People's Democratic Republic = 61.5). These differences in mortality rates are influenced by the differences in the availability and accuracy of death certification, level of cancer care including diagnosis and treatment, and the level of accessibility and use of care facilities supported by health care policies.^{16–18}

Childhood cancer survival

The global estimate of childhood cancer survival, based on very sparse data, is around 40%.⁵ In Asia, the 5-year net survival was estimated to be 39.6%, which is below the 60% target of the WHO GICC and lower than those in Europe (74.3%) and North America (83.0%).⁵ These estimates are model-derived and based on cross-sectional surveys of treatment access and abandonment of care for selected types of childhood cancer in selected geographic areas, and may provide an imprecise snapshot of the survival experience of children with cancer in Asian population.⁵ The CONCORD study compiles and disseminates survival data from population-based cancer registries, however so far only survival of children with leukaemia, brain tumours and lymphomas were reported.^{4,43,44}

Tables 1 and 2 present the survival of all childhood cancers and common types of childhood cancers in Asian countries defined in this review as reported in the CONCORD study and other population-based cancer registry data, as well as single- or multi-centre cohorts.^{3,4,10,15,34,43–87} The differences in survival were observed between and within the countries. These variations reflect the treatment outcome, the period of diagnosis, geographical region covered, age and characteristics of the study population, length of follow-up, tumour inclusion criteria (benign included or not) and statistical methods (net, overall, observed, relative, or postulated survival), as shown in [Supplementary Table S2](#). Postulated survival for some countries (all childhood cancers for Bangladesh, Philippines, Vietnam) were based on direct interviews with local health-care providers and epidemiologists because

population-based or hospital-based registries able to generate survival statistics were scarce.¹⁰ Because of the scarcity of population-based registries, which produce observed survival for the covered population, we reported such modelled or postulated percentage of survivors.

Among selected Asian countries, no reports were found from LICs. [Table 1](#) shows survival for all childhood cancers and 10 main diagnostic groups of childhood cancers reported in the reviewed studies carried out in 16 Asian countries. Survival was most often available for leukaemia, lymphoma, and brain or CNS tumours, as the CONCORD-3 study collected these three types of childhood cancer.^{4,43,44} Five-year survival of children with leukaemia (36.3–86.9%, from 9 countries)^{34,44,52,54,55,62,66,67,69,70,78,82,83} and lymphoma (30.0–92.1%, from 11 countries)^{4,34,51,52,54,55,62,69,78,82–84} was higher compared to that of brain or CNS tumours (31.6%–83.7%, from 10 countries)^{4,34,52,54,55,60,62,67,77–79,82,83} Survival of patients with retinoblastoma (31.6–100%, from 11 countries),^{34,52,54,62,71,72,76,78,81,82,85} renal tumours (12.5–94.1% from 7 countries)^{15,34,52,54,62,76,78,82} and germ cell tumours (38.0–95.3%, from 7 countries)^{34,52,54,62,82,83} were relatively high in HICs ([Table 1](#)). [Table 2](#) shows the survival of major childhood cancer subtypes in 18 Asian countries. Similarly, survival of patients with common leukaemia types, including acute lymphoblastic leukaemia (ALL, 31.8–100% from 16 countries)^{4,34,45,47,49,53,54,61,64,66,67,73,81,82,84,86} and acute myeloid leukaemia (AML, 23.2–80.1% from 12 countries),^{34,44,48,50,58,62,66,78,81,82,87} were available for many more Asian countries, than survival of patients with Burkitt lymphoma (16.7%–87.4%, from 4 countries)^{75,76,78,82} and Hodgkin Lymphoma (24.0–95.1, from 5 countries)^{62,74,76,78,82} ([Table 2](#)).

Overall childhood cancer survival was lower in LMICs (5.0–40.0%)^{10,62,84} than in UMICs (47.2%–71.9%),^{54,55,82,83} while in HICs the survival was above 70%^{3,52,78,81} ([Table 1](#)). The countries in which 5-year survival was below the GICC target of 60% survival were Bangladesh (5%, postulated 5-year survival),¹⁰ Vietnam (5%, postulated 5-year survival),¹⁰ Philippines (10%, postulated 5-year survival),¹⁰ Uzbekistan (30.0–40.0%, 5-year survival report from WHO)⁸⁴ and India (40.0%, 5-year overall survival).⁶² The CureAll framework of the WHO GICC focuses on six index cancers: ALL, Burkitt lymphoma, Hodgkin Lymphoma, retinoblastoma, Wilms tumour, and low-grade glioma.⁸⁸ For these cancers, countries with survival below 60% in [Tables 1](#) and [2](#) were Cambodia (3-year survival, ALL = 34.9%),⁵³ India (5-year survival, retinoblastoma = 48.1%, astrocytoma = 38.7%),⁶² Pakistan (5-year survival, ALL = 52.9%),⁷³ Philippines (5-year survival, retinoblastoma = 31.6%, Burkitt lymphoma = 16.7%, Hodgkin lymphoma = 24.0%),⁷⁶ Vietnam (5-year relapse free survival, ALL = 47.8%),⁸⁶ Indonesia (5-year survival, ALL = 44.3%),⁴⁵ and Mongolia (5-year survival, ALL = 34.3%).⁴⁵ On the other hand, survival in Asian

Locations ^a	All childhood cancers	Leukaemia		Lymphoma		Brain/CNS tumours		Neuro-blastoma	Retinoblastoma	Renal tumours	Hepatic tumours	Malignant bone tumours	Soft tissue sarcomas	Germ cell tumours
		CONCORD-3 (2010-2014) ⁴⁴	Other studies	CONCORD-3 (2010-2014) ⁴	Other studies	CONCORD-3 (2010-2014) ⁴	Other studies							
Lower-middle-income countries (LMICs)														
Bangladesh	5.0 ¹⁰ (0-14)				76.5 ⁵¹ (0-11)									
Pakistan									74.0 ^{b,72} (0-16, unilateral only)					
India	40.0 ⁶² (0-14)	47.8 ⁴⁴ (0-14)	36.3 ⁶² (0-14)		55.3 ⁶² (0-14)	38.7 ⁶² (0-14)	36.9 ⁶² (0-14)	48.1 ⁶² (0-14)	58.0 ⁶² (0-14)	10.5 ⁶² (0-14)	30.6 ⁶² (0-14)	36.3 ⁶² (0-14)	38.0 ⁶² (0-14)	
Philippines	10.0 ¹⁰ (0-14)													
Uzbekistan	30.0-40.0 ⁸⁴ (NS)				30.0 ⁸⁴ (NS)				31.6 ⁷⁶ (0-19)	12.5 ⁷⁶ (0-19)				
Vietnam	5.0 ¹⁰ (0-14)								90.3 ⁸⁵ (0-12)					
Upper-middle-income countries (UMICs)														
China	55.7-71.9 ^{54,55} (0-14)	56.3 ⁴⁴ (0-14)	52.2-70.5 ^{54,55} (0-14)	61.1 ⁴ (0-14)	58.8-64.7 ^{54,55} (0-14)	41.1 ⁴ (0-14)	41.2-69.9 ^{54,55} (0-14)	57.1-66.4 ^{54,57} (0-15)	75.0 ⁵⁴ (0-14)	72.0-86.7 ^{15,54} (0-14)	33.3-52.0 ^{54,55} (0-14)	52.6-80.5 ^{54,55} (0-14)	54.1 ⁵⁴ (0-14)	78.4 ⁵⁴ (0-14)
Malaysia		81.8 ⁴⁴ (0-14)	55.6-62.3 ^{69,70} (0-19)	85.0 ⁴ (0-14)	63.3 ⁶⁹ (0-14)	63.4 ⁴ (0-14)								
Mongolia									82.8 ⁻⁷¹ (0-6)					
Thailand	47.2-60.5 ^{82,83} (0-14 or 0-19)	59.4 ⁴⁴ (0-14)	43.7-63.1 ^{82,83} (0-14 or 0-19)	73.9 ⁴ (0-14)	53.1-75.1 ^{82,83} (0-14 or 0-19)	44.5 ⁴ (0-14)	31.6-44.4 ^{82,83} (0-14 or 0-19)	27.6-29.1 ^{82,83} (0-14 or 0-19)	61.2 ⁸² (0-14)	75.7 ⁸² (0-14)	27.6 ⁸² (0-14)	23.3 ⁸² (0-14)	48.6 ⁸² (0-14)	63.4-84.3 ^{82,83} (0-14 or 0-19)
High-income countries (HICs)														
Brunei	74.4 ⁵² (0-14)		80.1 ⁵² (0-14)		73.2 ⁵² (0-14)		52.5 ⁵² (0-14)	75.0 ⁵² (0-14)	80.0 ⁵² (0-14)	80.0 ⁵² (0-14)		50.0 ⁵² (0-14)	85.7 ⁵² (0-14)	87.5 ⁵² (0-14)
Hong Kong							66.8 ⁶⁰ (0-17)							
Japan	81.0 ³ (0-14)	84.7 ⁴⁴ (0-14)	79.6-83.7 ^{34,66,67} (0-14)	89.6 ⁴ (0-14)	86.8-90.2 ^{34,67} (0-14)	69.6 ⁴ (0-14)	58.0-64.7 ^{34,67} (0-14)	79.3 ³⁴ (0-14)	100 ³⁴ (0-14)	82.6 ³⁴ (0-14)	76.0 ³⁴ (0-14)	67.4 ³⁴ (0-14)	67.9 ³⁴ (0-14)	95.3 ³⁴ (0-14)
Singapore		86.9 ⁴⁴ (0-14)		92.1 ⁴ (0-14)		62.0 ⁴ (0-14)	72.2 ⁷⁷ (0-18)							
Republic of Korea	78.2 ⁷⁸ (0-14)	79.8 ⁴⁴ (0-14)	75.4 ⁷⁸ (0-14)	91.0 ⁴ (0-14)	86.6 ⁷⁸ (0-14)	60.3 ⁴ (0-14)	59.0-83.7 ^{78,79} (0-14 or 0-19)	73.9 ⁷⁸ (0-14)	95.5 ⁷⁸ (0-14)	94.1 ⁷⁸ (0-14)	69.5 ⁷⁸ (0-14)	77.4 ⁷⁸ (0-14)	77.2 ⁷⁸ (0-14)	94.6 ⁷⁸ (0-14)
Taiwan	81.5 ⁸¹ (0-17)	73.9 ⁴⁴ (0-14)		86.7 ⁴ (0-14)		54.8 ⁴ (0-14)		66.0 ⁸¹ (0-17)	95.9 ⁸¹ (0-17)		72.9 ⁸¹ (0-17)	73.7 ⁸¹ (0-17)		90.7 ⁸¹ (0-17)

^aAsian countries/locations were categorized into low-income countries (LICs), lower-middle-income countries (LMICs), upper-middle-income countries (UMICs), and high-income countries (HICs) based on the World Bank classification in 2022.²⁴ ^bSurvival other than 5-year survival. ^cIncludes cases diagnosed before 1990. Survival mostly include net survival if the data is available in the studies but also include other measures if the data is not available (Refer to [Supplementary Table S2](#)). Age ranges of the data included in the studies are indicated in bracket. NS: Not specified. Sources: see [Supplementary Table S2](#)

Table 1: Survival of patients diagnosed with cancer, overall and by and major cancer diagnoses in Asian countries in 1990s-2010s.

Locations ^a	Lymphoid leukaemia	All	AML	Hodgkin lymphoma	Non-Hodgkin lymphoma	Burkitt lymphoma	Medulloblastoma	Astrocytoma	Rhabdomyosarcoma	Wilms tumour	Osteosarcoma
Lower-middle-income countries (LMICs)											
Bangladesh			APL: 70.0 ^{b,50} (0-14)								
Cambodia		34.9 ^{b,53} (NS)									
India	38.7-79.2 ^{44,62} (0-14)	75.5 ⁴ (0-14)	30.3 ⁶² (0-14)	65.0 ⁶² (0-14)	46.6 ⁶² (0-14)			38.7 ⁶² (0-14)	36.4 ⁶² (0-14)	64.2 ⁶² (0-14)	43.6 ⁶² (0-14)
Pakistan		52.9 ⁷³ (1-18)		94.0 (NS) ⁷⁴	67.1 ^{b,75} (1-18)	63.9 ^{b,75} (1-16)					
Philippines	19.9 ⁷⁶ (0-19)			24.0 ⁷⁶ (0-19)		16.7 ⁷⁶ (0-19)					4.8 ⁷⁶ (0-19)
Uzbekistan		75.0 ⁸⁴ (NS)									
Vietnam		47.8 ⁸⁶ (0-15)	23.2 ^{b,87} (0-15)								
Upper-middle-income countries (UMICs)											
Armenia		70.0-100 ^{47,49} (0-19)	42.9 ⁴⁸ (0-19)								
China	66.3 ⁴⁴ (0-14)	57.7-62.0 ^{4,54} (0-14)	45.2 ⁴⁴ (0-14)		52.8 ⁵⁴ (0-14)		32.8 ⁴³ (0-14)	63.2 ⁴³ (0-14)	28.6 ⁵⁴ (0-14)	83.0 ⁵⁶ (0-14)	44.8 ⁵⁴ (0-14)
Indonesia		31.8 ^b -44.3 ^{45,64} (0-14 or 0-18)							71.7 ⁶⁵ (0-14)		29.4 ⁶³ (2-18)
Malaysia	85.0 ⁴⁴ (0-14)	82.3 ⁴ (0-14)	80.1 ⁴⁴ (0-14)								
Mongolia		34.3 ⁴⁵ (0-14)									
Thailand	68.0 ⁴⁴ (0-14)	52.3-65.9 ^{4,82} (0-14)	26.5-40.0 ^{44,82} (0-14)	60.6 ⁸² (0-14)	49.1 ⁸² (0-14)	77.0 ⁸² (0-14)	27.6-49.6 ^{43,82} (0-14)	26.6 ^{43,82} (0-14)	26.7 ⁸² (0-14)		
High-income countries (HICs)											
Hong Kong		77.9 ^b (10-18)-87.6 ^b (1-9) ⁶¹	Non-M3: 64.0 ⁵⁸ (0-17)				63.1 ⁶⁰ (0-17)			94.4 ⁵⁹ (0-18)	
Japan	89.2 ⁴⁴ (0-14)	82.3-87.6 ^{4,34,66,67} (0-14)	71.1-77.9 ^{34,44,66} (0-14)				73.1 ⁴³ (0-14)	73.4 ⁴³ (0-14) Grade I and II: 96.5 ⁴³ (0-14)	59.1 ³⁴ (0-14)	92.1 ⁶⁸ (0-17)	
Singapore	91.9 ⁴⁴ (0-14)	88.6 ⁴ (0-14)	76.4 ⁴⁴ (0-14)				50.0-54.7 ^{43,77} (0-18)	69.5-95.7 ^{43,77} (0-18) Grade I and II: 94.5 ⁴³ (0-14)			
Republic of Korea	81.0-85.4 ^{44,78} (0-14)	84.4 ⁴ (0-14)	59.7-63.4 ^{44,78} (0-14)	95.1 ⁷⁸ (0-14)	78.8 ⁷⁸ (0-14)	87.4 ⁷⁸ (0-14)	68.7-70.0 ^{43,79} (0-19)	43.5-97.0 ^{43,78,79} (0-19) Grade I and II: 83.1 ⁴³ (0-14)	78.8 ⁷⁸ (0-14)	97.2 ⁸⁰ (0-18)	81.5 ⁷⁸ (0-14)
Taiwan	78.2 ⁴⁴ (0-14)	76.5 ⁴ (0-14)	58.0 ⁴⁴ (0-14)		84.8 ^{b,81} (0-17)		62.7 ⁴³ (0-14)	53.0 ⁴³ (0-14) Grade I and II: 84.1 ⁴³ (0-14)	62.6 ⁸¹ (0-17)	90.2 ⁸¹ (0-17)	73.7 ⁸¹ (0-17)

^aAsian countries/locations were categorized into low-income countries (LICs), lower-middle-income countries (LMICs), upper-middle-income countries (UMICs), and high-income countries (HICs) based on the World Bank classification in 2022²⁴

^bSurvival rates other than 5-year survival. Age ranges of the data included in the studies are indicated in bracket. NS, Not specified. Sources: see [Supplementary Table S2](#)

Table 2: Survival of patients with selected cancer subtypes in Asian countries in 1990s–2010s.

HICs were over 60% and comparable to those in Europe and North America (Table 2).^{4,5} The described survival disparities highlight the need for significant efforts to support Asian countries with limited resources to achieve the WHO GICC goal.

Prevalence of childhood cancer survivors

To predict the demand for medical care and social resources for childhood cancer survivors, the number of people with cancer who remain alive at a specified point in time in a population, known as prevalence of cancer survivors, is an essential measure.⁸⁹ Both short and long-term prevalence estimates are important for monitoring childhood cancer survivorship and planning for specific needs.⁸⁹ However, the analysis of prevalence requires many years of incidence data and information on the vital status of patients which is currently unavailable in most Asian countries. A literature search revealed only one paper reporting on observed prevalence of childhood cancer survivors in Asia.⁹⁰ Based on data collected in population-based Osaka Cancer Registry in Japan from 1975 to 2019, 5,252 childhood cancer survivors (age-standardised prevalence = 987 per million) aged 0–59 years lived in Osaka at the end of 2019.⁹⁰ Extrapolating this figure to the whole Japan yields 73,013 childhood cancer survivors.⁹⁰ In Osaka, the 5-year age-standardized prevalence per million increased from 194 in 1979 to 417 in 2019, while the 10-year prevalence increased from 391 in 1984 to 715 in 2019.⁹⁰ The increasing prevalence indicates a growing need for support of childhood cancer survivors as they attain their adult age. The Japan Children's Cancer Group at the National Center for Child Health and Development Data Center has also established a data infrastructure for long-term follow-up to collect and disseminate data with support from the Ministry of Health, Labor and Welfare Research for Promotion of Cancer Control Programmes, which is also expected to contribute to survivorship research such as monitoring late effects and quality of life in childhood cancer survivors. The data collection platform uses Amazon Web Service, and REDCap®, which is provided free of charge for academic use by Vanderbilt University, USA. REDCap® is currently used in more than 150 countries,^{91,92} so it could potentially be introduced in other countries.

Challenges in data collection and lack of population-based cancer registries

Summarizing the childhood cancer statistics in Asia poses a major challenge, particularly due to the lack of population-based cancer registries, which generate incidence and survival data that can be used in international studies. Unfortunately, such registries cover less than 5% of the childhood population in Asia.²⁹ The Supplementary Table S1 shows the status of cancer

registration in Asian countries as confirmed by reports from international joint research.^{4,29,93} While Republic of Korea, Singapore, Brunei Darussalam, Mongolia, and Japan have a national coverage, other countries were represented by registries covering variable proportion of their national childhood population,⁹⁴ which makes it difficult to assess the overall picture of epidemiology and impedes definition of the healthcare needs in many Asian countries.

In many LMICs, the unavailability of advanced diagnostic technologies, lack of a robust data infrastructure, and inherent limitations of the local healthcare system can result in delayed diagnoses and underreporting of cancer cases.⁹⁵ Most Asian countries does not dispose of comprehensive national death registration systems typical for countries in Europe or North America. The lack of a national electronic medical record system that is linked with a cancer registry and death registry is a barrier to long-term follow-up and estimation of survival. Also, cultural and socio-economic factors such as treatment refusal and abandonment can influence the reporting. The mentioned factors lead to disparities in understanding the true burden of childhood cancer and hinder implementation of effective interventions.

The CureAll framework and action in SIOP Asia Improving social capital through the CureAll framework

The CureAll framework¹⁹ has been proposed as a part of the strategy to support the social implementation of the WHO GICC in countries with diverse national contexts. The CureAll framework is aimed to increase the capacity of countries to provide quality services for children with cancer, and to increase prioritization of childhood cancer at the global, regional and national levels. This framework is a technical package based on four pillars (Centers of excellence, Universal health coverage, Regimens of management, and Evaluation and monitoring) with three types of support (Advocacy, Leveraged financing, Linked governance) (Fig. 4).⁸⁸ The CureAll framework is implemented in “focus countries” receiving priority support. Focus countries are those that met criteria defined in the WHO GICC conceptualization framework, and where the implementation of the CureAll priority actions or projects is led by the Ministry of Health. In Asia, they included Kyrgyzstan, Uzbekistan, Lebanon, Pakistan, Palestine, Syria, Bhutan, Myanmar, Nepal, Sri Lanka, Mongolia, Philippines, and Vietnam by February 2024. In some focus countries, a national strategic action plan has been developed and is underway with specific plans to develop insurance systems, cancer registries, and data centers. The CureAll framework is expected to contribute to reducing disparities in childhood cancer survival in Asian children by providing support tailored to circumstances in each country.

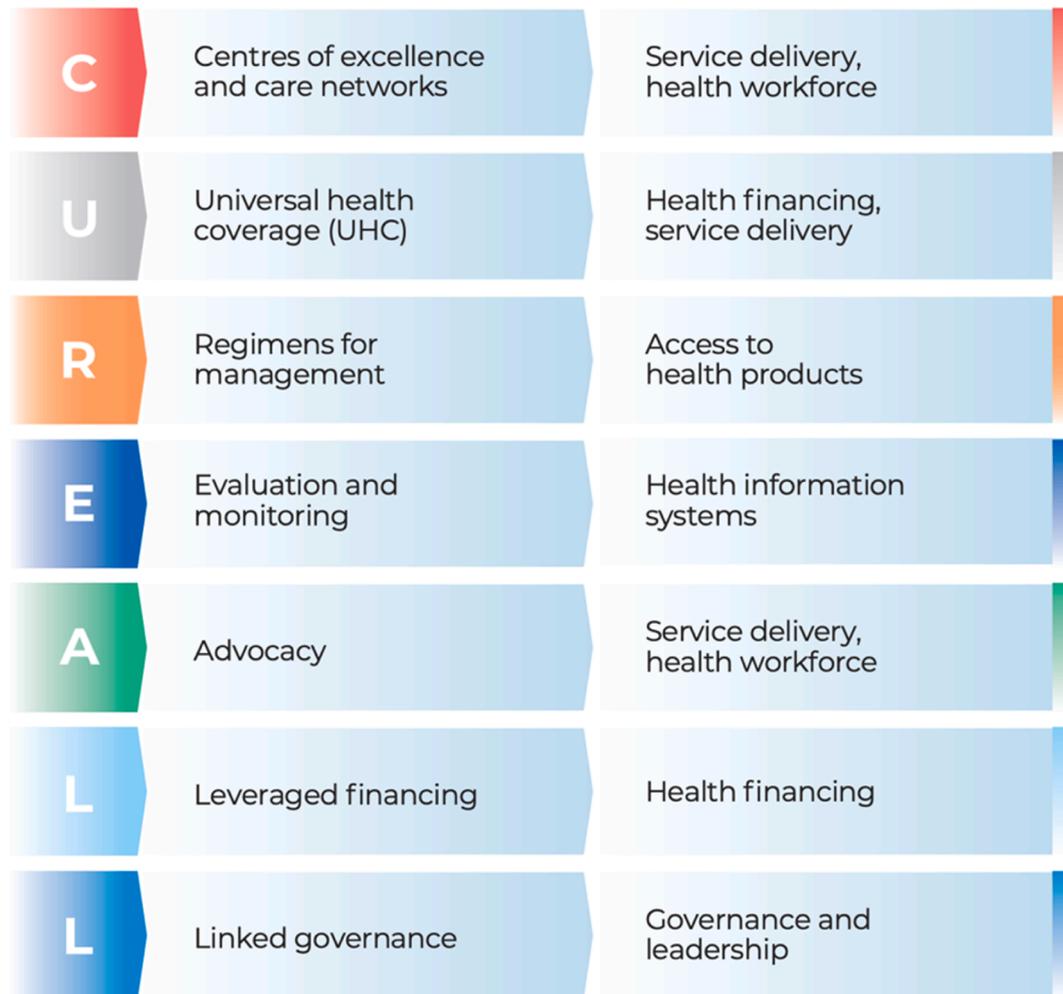


Fig. 4: The health system building blocks of the CureAll Framework Source: WHO GICC.¹⁹

Fostering international collaboration through SIOP Asia

Regional collaboration enhances knowledge and resource sharing: Initiatives such as regional cancer networks, research collaborations, and cross-border training programs foster the exchange of expertise, helping to standardize care practices and improve overall outcomes. To promote WHO GICC in the Asian region effectively, SIOP introduced a classification for each WHO regional office to which Asian countries belong. This classification is developed based on the cooperation of the Asian branch (SIOP Asia) with WHO Regional Offices and divides the Asian regions into four sub-regions as shown in [Supplementary Table S1](#). The subgroup consists of the four WHO regional offices, based on geographical and cultural backgrounds ([Supplementary Figure](#)). In addition, international cooperation to improve paediatric cancer care is expected to progress in the future taking this subgrouping into account. APHOG, established in 2012 also supports and strengthens this network. Resources

for research funding are limited in the field of childhood cancer, yet the development of data infrastructure for systematic data collection requires significant resources. Using this network, cooperation in data collection is being considered which integrate data already generated for clinical research in each country and create a centralized clinical database as Asian Hub; this could foster multinational collaboration to build a childhood cancer database for the region and provide data source for the population-based cancer registries.

Establishing childhood cancer registries in Asian countries

“Strengthening and linking cancer registries” is one of the 10 CureAll core projects of the WHO GICC,^{88,96} and to address the issue, various efforts including the establishment of population-based cancer registries, clinical data centers, and standardization of data management operations are progressing as international or national projects in some Asian countries.⁹⁷

Targeting Childhood Cancer through the Global Initiative for Cancer Registry Development (ChildGICR)

In May 2020, St. Jude Children's Research Hospital and IARC started a bilateral collaboration "Targeting Childhood Cancer through the Global Initiative for Cancer Registry Development (ChildGICR)".⁹⁸ The overall aim of this collaboration is to improve the quality and availability of data on cancer in children, particularly in countries with limited resources and use these data in international studies. Since 2021, 20 graduates of the ChildGICR Masterclass have helped to disseminate knowledge to more than 100 participants from 27 countries through ChildGICR Childhood Cancer Registration online courses. Three such courses were streamed from Hanoi, Vietnam, Chennai, India, and Tbilisi, Georgia.^{98,99} A total of 88 participants from 16 countries including 13 Asian countries (Armenia, Azerbaijan, Brunei Darussalam, Georgia, India, Indonesia, Malaysia, Myanmar, Nepal, Pakistan, Malaysia, Myanmar, the Philippines, Sri Lanka, Vietnam) acquired basic knowledge on childhood cancer registration, shared their approach to implementation of childhood cancer registration in their countries, and held discussions on promoting childhood cancer registration in their context.^{98,99}

Domestic contributions to promoting childhood cancer registries in Asia

International collaborations, the crucial driver of the progress in data provision and use, spring from domestic efforts, the large part of which must be focused on ensuring sustainability. In 2022, a population-based childhood cancer registry was newly established in Chennai through the collaboration of GICC and GICR members. A recent survey conducted at this registry identified technical limitations, poor record keeping, lack of details in case records, and lack of human resources as the impediments to sustaining a registry.⁹⁷ Factors such as knowledge, willingness to share high-resolution data, understanding the needs for and benefits of implementing a childhood cancer registry, professional self-efficacy, operational infrastructure, and collaboration emerged as drivers of success.⁹⁷

While some countries/regions have a well-established healthcare infrastructure and resources, others rely heavily on regional partnerships and external support to develop effective data collection frameworks. Additionally, assessment of healthcare, especially the rare childhood cancers, requires direct comparison of collected data with other countries to promote data quality, support research and produce new knowledge. For example, participation in studies like IICC or CONCORD includes provision of files of individual cancer records to enable data validation and flexibility of analyses. While protecting personal data is indisputable, advancing childhood cancer research can

only be ensured through learning from the shared data. Personal data should always be protected, and available for international research.

Governments should support population-based cancer registration within national health strategies, to be able to plan for sufficient investment in healthcare infrastructure, workforce training, and evaluate the progress. Regional collaboration, where more advanced systems support others in capacity building, is critical to standardize data collection across countries. Additionally, investing in technology—such as electronic health records and data management systems—can improve the accuracy and efficiency of data collection.

Moreover, explaining the purpose of data collection to the policy makers and to the public is part of the fight for reduction of childhood cancer burden. Integrating registry data into health policy-making processes will help guide decisions on resource allocation and treatment protocols. Continuous advocacy from healthcare providers and civil society organizations remains essential to maintain focus on paediatric oncology and to advocate for necessary policy reforms based on cancer registry data.

Conclusions

In this review of the status of childhood cancer burden in Asia, we highlighted epidemiological indicators of childhood cancer in Asia, as well as the disparities in data availability and health care systems, which impact childhood cancer outcome. Surveillance of childhood cancer should expand in most Asian countries and be monitored on national and international level. Epidemiological data are essential to better understand the burden of childhood cancer and provide hope to children and their families. National, regional and international networks of stakeholders are rallying to improve data, promote research, and improve thus childhood cancer care in Asia.

Contributors

CKL conceived this study. KN led the writing of the original draft. KN conducted a search on incidence and mortality, YTC and CSL on survival, and MK on prevalence. MK collected information on the CureAll framework and action in SIOP Asia. GNH collected information on the activities of ChildGICR and childhood cancer registries in Asia. ESF, KPJ and AN provided critical input. All authors were involved in the data interpretation, draft review, and approval of the manuscript's final version.

Data sharing statement

All data used in this review are publicly available.

Declaration of interest

All authors declare no conflicting interests associated with this study.

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Where authors are identified as personnel of the International Agency for Research on Cancer/World Health Organization, the authors alone are responsible for the views expressed in this article and they do not necessarily represent the decisions, policy, or views of the International Agency for Research on Cancer/World Health Organization.

Appendix A. Supplementary data

Supplementary data related to this article can be found at <https://doi.org/10.1016/j.eclinm.2025.103554>.

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