ANNUAL REPORT

2025

Childhood Cancer Registry of Switzerland

Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry

Main highlights in 2025

Visionary project “Projekt Zielbild Krebsregistrierung in der Schweiz»

The national Childhood Cancer Registry (ChCR) made a substantial contribution to the visionary project “Projekt Zielbild Krebsregistrierung in der Schweiz” of the Federal Office of Public Health (FOPH) and the Conference of the Cantonal Health Directors (GDK/CDS) which explores options for a more forward looking and efficient Swiss cancer registration system. This project includes representation from all stakeholders.

National paediatric oncology dataset

Thanks to the expertise of representatives of the Swiss paediatric oncologist the ChCR was able to define the further development of the national paediatric oncology dataset. The results are currently under discussion for the implementation into the national data set by the National Agency for Cancer Registration (NACR) by 2027.

Migration to the registration software NICERStat

November 2025 marked the successful migration of the ChCR to NICERStat, aligning with the software used by the adult cancer registries in Switzerland. Much of the year 2025 was dedicated to preparatory work leading up to this migration.

Table of contents

1. The Childhood Cancer Registry of Switzerland (ChCR)

The Childhood Cancer Registry of Switzerland (ChCR) is mandated by the federal government to record, monitor, and report on cancer cases occurring before the age of 20 across Switzerland. The ChCR records detailed information on newly diagnosed tumours, as well as data on treatments, disease progression, relapses, and late effects.

The data are used for monitoring, i.e. the surveillance of key indicators related to cancer in Switzerland, such as the occurrence of new tumours (incidence) and the cure rate (survival); see Chapters 2 and 5.

The routine data recorded are regularly analysed and published on the ChCR website. The ChCR also transmits data to the Federal Statistical Office for the annual cancer monitoring report "Cancer in Children" and for the Swiss Cancer Report, which is published every five years. The Cancer Health Report aims to go beyond routine reporting by examining current topics and health policy issues related to cancer and providing recommendations. The first health reporting on cancer (HRC) was published in 2024 and describes the risk that individuals with a history of cancer will develop a second primary tumour (i.e., a new tumour).

On the other hand, the comprehensive dataset of the ChCR enables participation in international and national research studies aimed at understanding the occurrence of cancer, improving treatment, and ensuring that affected young people have a future with minimal long-term consequences and optimal quality of life; see Chapters 6 and 10. Hospitals can also request their patients' data for quality assurance purposes.

The Childhood Cancer Registry was originally established as a national registry by the Swiss Paediatric Oncology Group (SPOG) on a voluntary basis and has been hosted and led at the Institute of Social and Preventive Medicine at the University of Bern (ISPM) since 2004. Since the Cancer Registration Act (CRA) came into force on 1 January 2020, maintaining a childhood cancer registry in Switzerland has been a federal responsibility, it is still managed by the ISPM under mandate from the Federal Office of Public Health (FOPH). Since then, reporting cancer cases is mandatory for physicians, hospitals, and laboratories. The law also regulates patients' rights (right to information, right to object to registration, and right to access their own data); see Cancer Registration in Switzerland.

In this annual report we illustrate how the ChCR operates and we presents as selection of recent results.

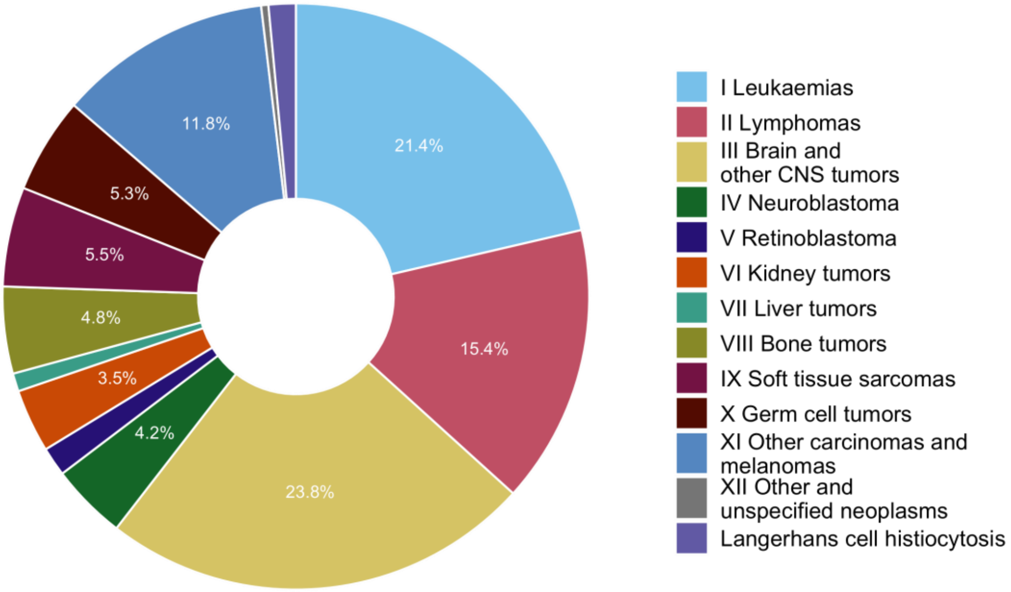
2. Facts and figures on cancer in children and adolescents

This chapter addresses frequently asked questions about cancer in children and adolescents: How many cases occur annually in Switzerland? Which types of cancer are most common? What are the chances of survival? How many affected individuals currently live in Switzerland?

Compared with adults, cancer is rare in children and adolescents. **The ChCR registers an average of 358 cancer cases each year:** 244 in children and 114 in adolescents (average from 2014-2023). **This corresponds to 21 new cases per 100,000 children and adolescents per year.**

Children and adolescents show a distinct pattern of cancers compared with adults. According to the International Classification of Childhood Cancer (ICCC-3[1]), these cancers are categorized into 12 main groups. **The most common tumours are those of the central nervous system (CNS) (24%), leukaemias (21%), and lymphomas (15%)**, which together account for more than half of all cases (G2.1). Other cancers arise from embryonic tissue, including neuroblastomas (4%), kidney tumours (4%), liver tumours (1%), germinal cell tumours (5%), and retinoblastomas (2%). Germinal cell tumours occur in the gonads (ovaries and testes), but also in other locations, such as the brain. Soft tissue sarcomas (6%), malignant bone tumours (5%), and carcinomas and melanomas (12%) are also observed. Langerhans cell histiocytosis (2%), which has not consistently been covered by the ICCC-3 classification in the past, is also recorded by the ChCR and included in the statistics due to its similar treatment approach.

G2.1 Proportion of registered cancer cases in children and adolescents by cancer type according to ICCC-3 and Langerhans cell histiocytosis, based on data from 2014-2023. (Proportions not listed are below 2%.)



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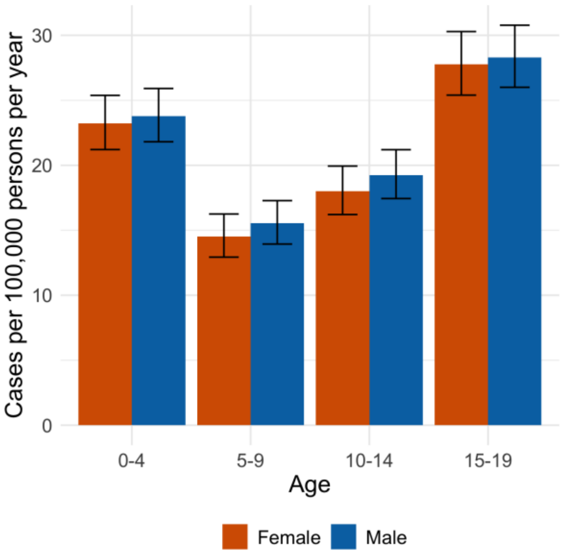
[1] Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, Third Edition. *Cancer* 2005;103:1457-67.

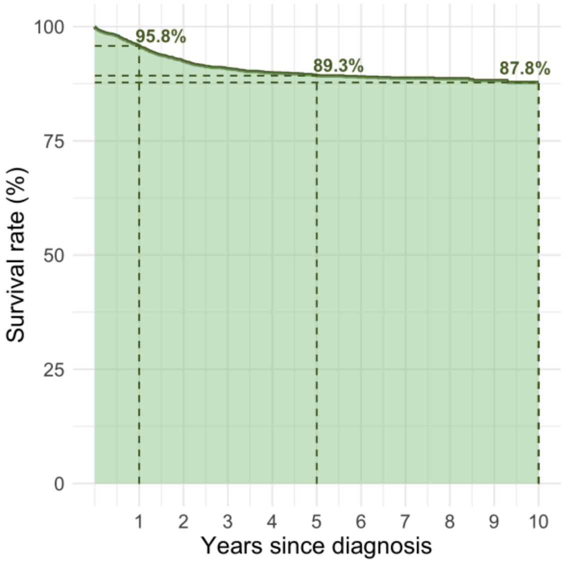
G2.2 Incidence of cancer in children and adolescents in Switzerland: Crude rates per 100,000 person-years by age and sex, based on data from 2014-2023.



Cancer occurs slightly more frequently in male children and adolescents than in females, and incidence rates vary with age (G2.2). Preschool children are more frequently affected than older children. In adolescence, the incidence rises again.

Thanks to major advances in cancer therapy, the most affected children and adolescents survive. One year after diagnosis, the survival rate is about 96%. Almost 90% of those affected survive five years and almost 88% are still alive after ten years (G2.3).

G2.3 Cancer survival of children and adolescents in Switzerland: Rate over time, based on data from 2014-2023.



At the end of 2023, around 3,000 children and adolescents living in Switzerland had been previously diagnosed with cancer. This corresponds to approximately 166 per 100,000 individuals aged 0 to 19 years. The analysis is limited to ages 0–19 because reliable estimates cannot be calculated for all ages. Owing to rising survival rates, this number is expected to increase in the future. Detailed results on cancer in children and adolescents are presented in Chapter 5.

3. The ChCR introduces itself

The National Childhood Cancer Registry today

Although the maintenance of the Childhood Cancer Registry of Switzerland has been a federal responsibility since the enactment of the Cancer Registration Act, the Childhood Cancer Registry in Switzerland has, in fact, existed for nearly 50 years. By the end of 2025, data from over 14,000 patients have been recorded in the ChCR.

About the history

The ChCR originated from the Swiss Childhood Cancer Registry (SCCR), which was established in 1976 on a voluntary basis by the Swiss Paediatric Oncology Group (SPOG). This is the association of the nine Swiss paediatric oncology departments that provide treatment for children and adolescents with cancer. Initially, only participants in clinical treatment studies were registered. However, from 1981 onwards, all patients treated in Switzerland were included, and since 1992, the long-term course and late effects in cured patients have also been recorded. Despite the absence of mandatory reporting, the registration of children up to the age of 15 was almost complete from 1990 onwards; currently it remains the only nationally comprehensive cancer registry in Switzerland.

Why is a dedicated childhood cancer registry necessary?

All childhood cancers are rare tumours, and their assessment requires specialised expertise as well as national and international collaboration in the field of paediatric oncology and cancer registration. Therefore, childhood cancers are registered at the national level, whereas adult cancer registration is carried out at the cantonal level.

Cancer diagnosed are coded by specialised staff, in accordance with international and national guidelines and in consultation with international experts. In addition to national and international classifications also used for adult cancers such as the International Classification of Diseases (ICD-10), the International Classification of Diseases for Oncology (ICD-O), and the Tumor size (T), lymph-Node involvement (N), and distant Metastasis (M) classification, childhood cancer cases are coded using child-specific standards, including the ICCC-3 and the Toronto Childhood Cancer Staging Guidelines.

The core team of the Registration, Coding and Data Quality (RCD) department, from left to right: Sophia della Valle, Mirjam Weiss, Maria Hammer, Christina Çinar-Kaufmann, Gabrielle Vautravers Bayram)

Claudia Kuehni, Head ChCR

The entire ChCR team, from left to right: Grit Sommer, Ben Spycher, Ursula Kühnel, Gabrielle Vautravers Bayram, Christina Çinar-Kaufmann, Alex Junghans, Sophia della Valle, Mirjam Weiss, Marina Haller (missing: Maria Hammer).

The operational management and work of the ChCR is carried out by a small team of 11 part-time employees (6.2 full-time employees).

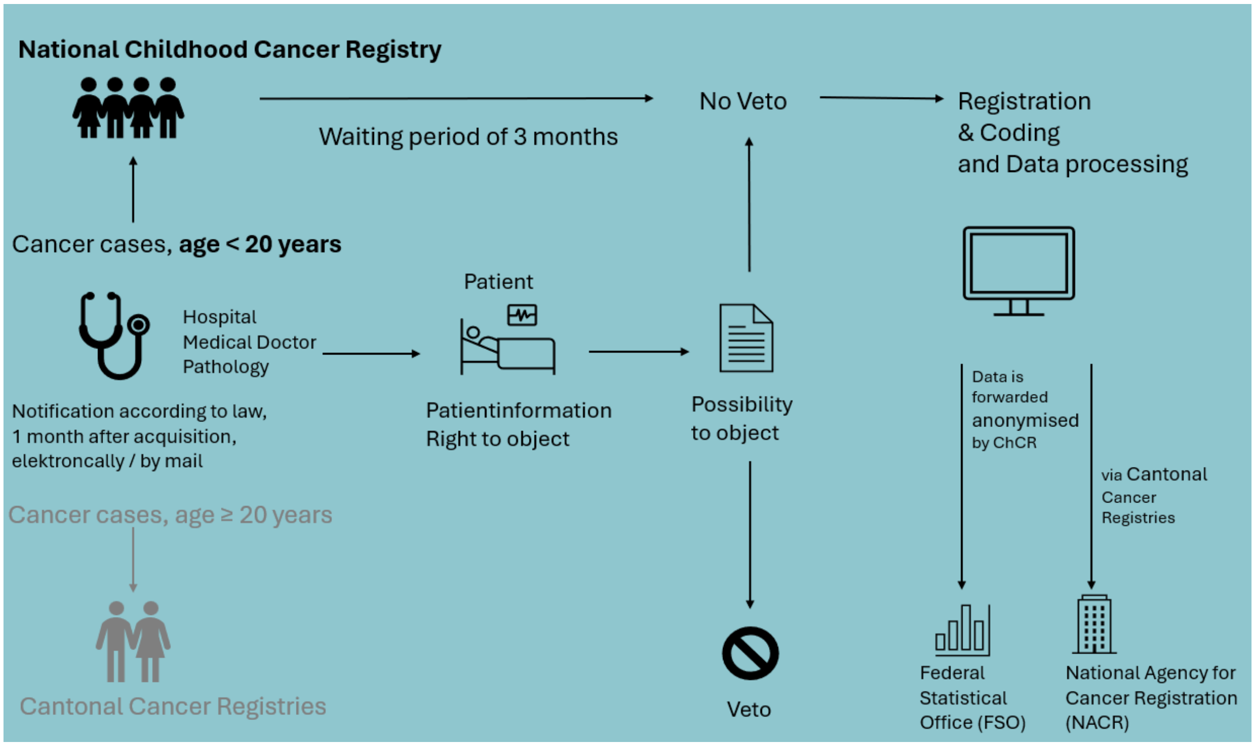
Head	Claudia Kuehni
Coordination	Ursula Kühnel
Registration & Coding	Sophia della Valle, Christina Çinar-Kaufmann, Maria Hammer, Gabrielle Vautravers Bayram, Mirjam Weiss
Statistics	Ben Spycher, Marina Haller
Data Requests	Grit Sommer, Alex Junghans

The affiliation with the University of Bern enables the ChCR to be in touch with scientific research and to provide professional support for registry-related studies. The ChCR team collects and codes the data required for research into medical and epidemiological questions. The Statistics, Reporting and Data Management team performs routine analyses and provides data to researchers. It serves as the contact point for external researchers and data requests by authorities, physicians, and patients.

The core team for Statistics, Reporting and Data Management from left to right: Ben Spycher, Marina Haller, Grit Sommer, Alex Junghans.

4. How does data get into the ChCR?

All professionals who diagnose or treat notifiable tumours are obliged to report data to the cancer registry. The corresponding rights and obligations, deadlines, and data specifications are defined by law and ordinance (Art. 3 – 4 Cancer Registration Act (CRA), Art. 2, 4 – 9, 11, 13, 16, 28 Cancer Registration Ordinance (CRO)).



Data flow in the national Childhood Cancer Registry (individuals under 20 years of age)

The process of recording cancer cases in children and adolescents under the age of 20 involves several steps:

1. **Reporting by medical facilities**
   Once a case of cancer is diagnosed, hospitals, physicians, and pathology laboratories are legally obliged to report it to the ChCR within one month. This can be done electronically or by mail.

2. **Patient information and right to object**
   The child or its legal representative is informed about the registration and may object (veto) to the registration at any time.

3. Processing of data

- If no objection is lodged, the case is registered by the ChCR, the tumour is coded, and the data are processed for the national cancer dataset and cancer monitoring.
- If the objection is submitted within a waiting period of three months after the receipt of the first report by the cancer registry, the data will be deleted.
- If the objection is submitted later, the data are anonymised.

Further information can be found in the patient information and the population information

4. Forwarding of the data

Following registration, the data are processed by the ChCR and once per year forwarded:

- The ChCR provides the cantonal cancer registries with all basic data to ensure complete cancer incidence coverage among the population of each canton.
- From there, the data are forwarded anonymously to the National Agency for Cancer Registration (NACR) for inclusion in the national cancer dataset.

What happens with the data?

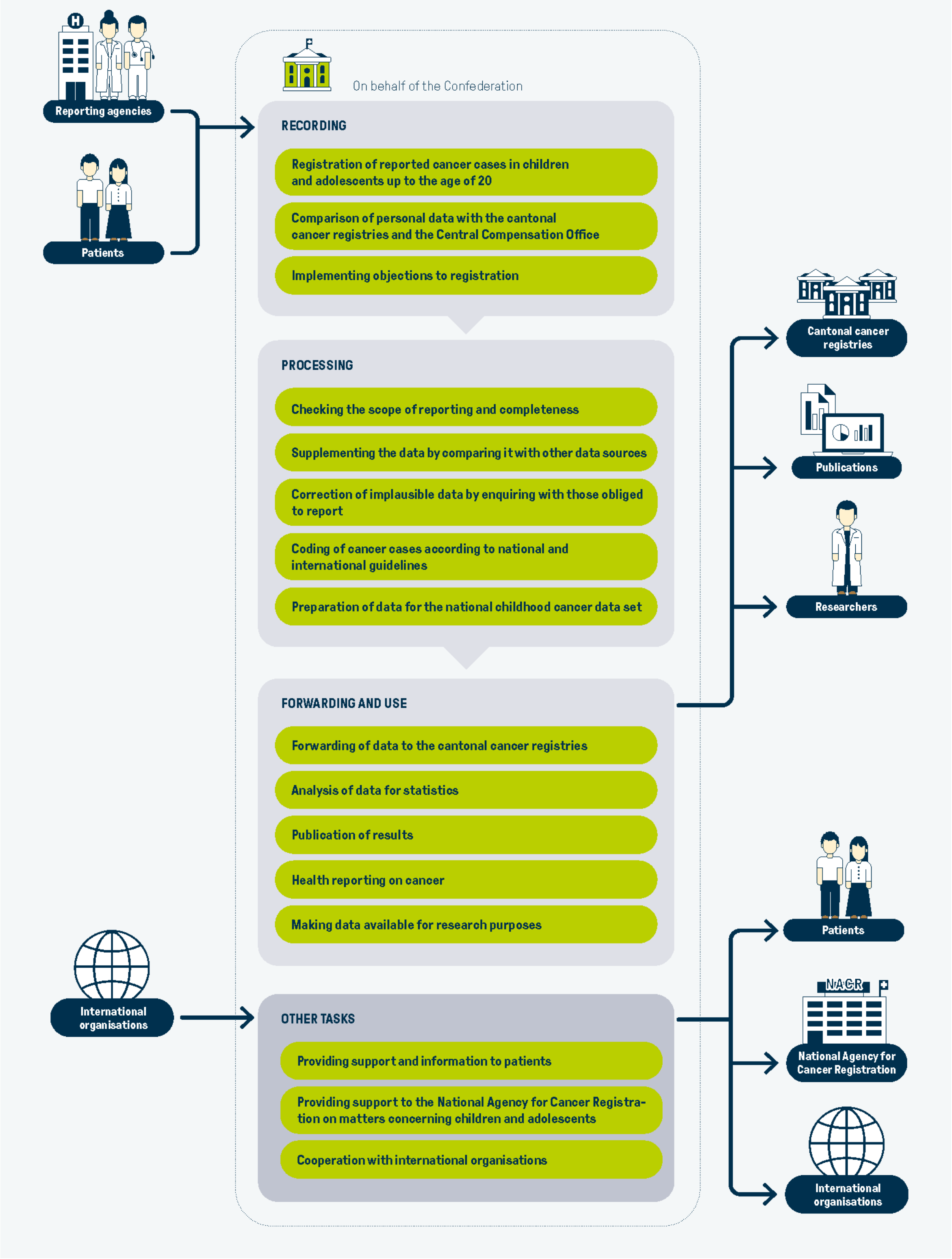
First, the ChCR carefully checks and processes all the data to ensure quality and completeness (see graphics for details). Furthermore, data are compared, validated, and supplemented with data from other registries and statistics – like hospital records and cause-of-death statistics from the FSO – to make sure no cancer cases are missed out (case ascertainment).

The ChCR regularly analyses this data and shares the Statistics and results every year on their website (see also Chapters 2 and 5). It supports research projects (see Chapter 7, Latest developments in childhood cancer research and Chapter 10, 2025 publications based on ChCR data) and data requests from authorities, physicians and patients, or their legal representatives (see Chapter 6, Value of ChCR data).

Each year the ChCR receives a data request by the FSO and delivers cancer statistics (anonymized data, no additional information added) for the publication Childhood cancer statistics on the FSO webpage. These data are.

The ChCR works closely with paediatric oncologists to ensure that the national paediatric oncology dataset meets current needs, ensuring that the data collected are most useful for research and evaluation purposes.

Tasks of the National Childhood Cancer Registry of Switzerland



RECORDING

- Registration of reported cancer cases in children and adolescents up to the age of 20
- Comparison of personal data with the cantonal cancer registries and the Central Compensation Office
- Implementing objections to registration

PROCESSING

- Checking the scope of reporting and completeness
- Supplementing the data by comparing it with other data sources
- Correction of implausible data by enquiring with those obliged to report
- Coding of cancer cases according to national and international guidelines
- Preparation of data for the national childhood cancer data set

FORWARDING AND USE

- Forwarding of data to the cantonal cancer registries
- Analysis of data for statistics
- Publication of results
- Health reporting on cancer
- Making data available for research purposes

OTHER TASKS

- Providing support and information to patients
- Providing support to the National Agency for Cancer Registration on matters concerning children and adolescents
- Cooperation with international organisations

Source: Cancer registration in Switzerland.

Which tumours must be reported to the ChCR?

ICD-10 Codes	Notifiable diseases
C00-C97	Malignant neoplasms (except basal cell carcinoma of skin)
D00-D03, D05-D09	In situ neoplasms
D32, D33, D35 (D35.2, D35.3, D35.4)	Benign neoplasms of the meninges and central nervous system and benign neoplasms of endocrine glands of the head/brain (pituitary gland, pineal gland, ductus craniopharyngealis)
D37-D48	Neoplasms of uncertain or unknown behaviour
D61	Other aplastic anaemias
D76	Other specified diseases with participation of lymphoreticular and reticulohistiocytic tissue

All malignant cancers assigned with a C code in the ICD are subject to the reporting obligation. In addition, certain benign or uncertain neoplasms are also registered and assigned a D code. Although these diseases are not clearly malignant, they can nonetheless be dangerous due to their location (for example, in the brain) or their widespread distribution in the body and may require cancer therapy or long-term monitoring. In children, these primarily include all benign neoplasms of the brain and central nervous system, aplastic anaemias, histiocytosis, and certain other rare diseases. Some of these rare diagnoses are not recorded for adults in Switzerland. More detailed information can be found in the Information Sheet for Reportable Cancers.

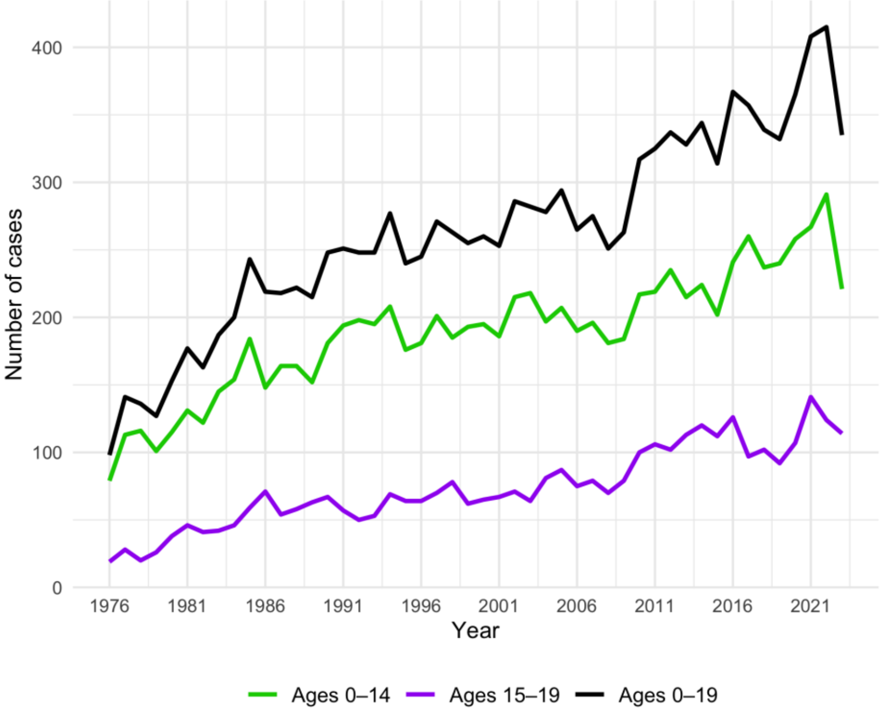
5. Results

This chapter shows the annual number of new cases (incidence rate) and cancer-related deaths (mortality rate) per 100,000 persons per year by diagnostic group, sex and age. It also reports survival rates and the number of affected persons currently living (prevalence) in the Swiss population. We distinguish cancer groups as defined by the 12 main groups of ICCC-3 as well as Langerhans cell histiocytosis, for which no mortality is reported due to the small number of deaths. Other diseases that must be notified to the registry, some of which have only been registered since 2020 (see notifiable diseases in Chapter 4), are not included in the analyses. The methodology used is described in detail in the report Statistical Methods for Cancer Reporting in Switzerland (available in English only).

Methodological note

For children aged 0-15 years, the result are based on the observed case counts (i.e., the actual registered cases), as the ChCR has covered this group nationwide since its establishment in 1976. For adolescents aged 16-19 years, nationwide registration was incomplete before 2020 when the Cancer Registration Act came into force. Before 2020 data collection relied heavily on data exchange with cantonal registers, and not all cantons had a registry. Therefore, for incidence calculations, the observed case counts in adolescents were not used directly. Instead, they were extrapolated to estimate the total number of cases that would have been expected under complete national registration coverage.

G5.1 Annual number of cancer cases registered by the ChCR among children (0-14 years) and adolescents (15-19 years) residing in Switzerland, separately and combined (0-19 years), based on data from 1976 to 2023. Included are cancers from the main groups of the ICCC-3 as well as Langerhans cell histiocytosis.



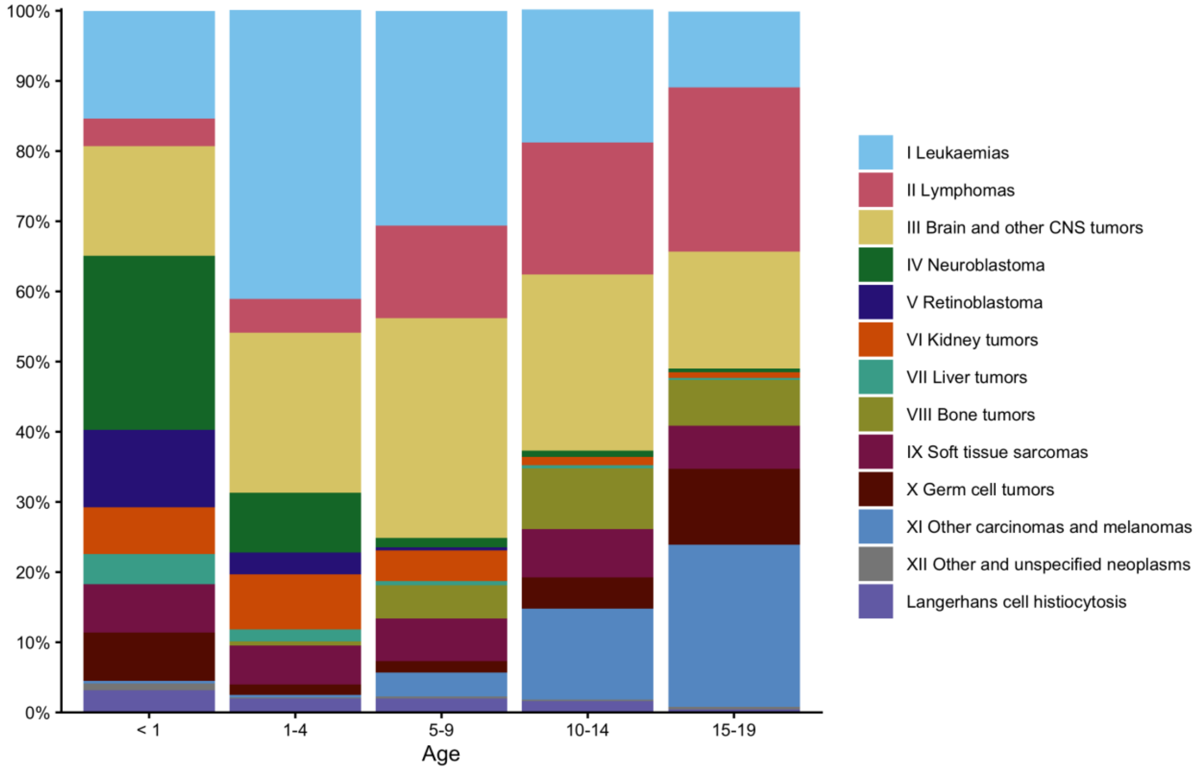
Registered cancer cases

Between 1976 (the foundation of the ChCR) and December 31, 2023, the ChCR registered a total of 12,635 cancer cases and Langerhans cell histiocytosis diagnosed at age 0-19 years. These tumours were diagnosed in 12,451 patients. The number of cases registered in the ChCR has increased over time (G5.1), partly due to improvements in cancer registration. However, the trend also reflects an effective increase in cancer cases due to the growing population in Switzerland and, possibly, increasing incidence rates (see G5.4). As can be seen from Figure G5.1, the number of cancer cases registered varies considerably from year to year.

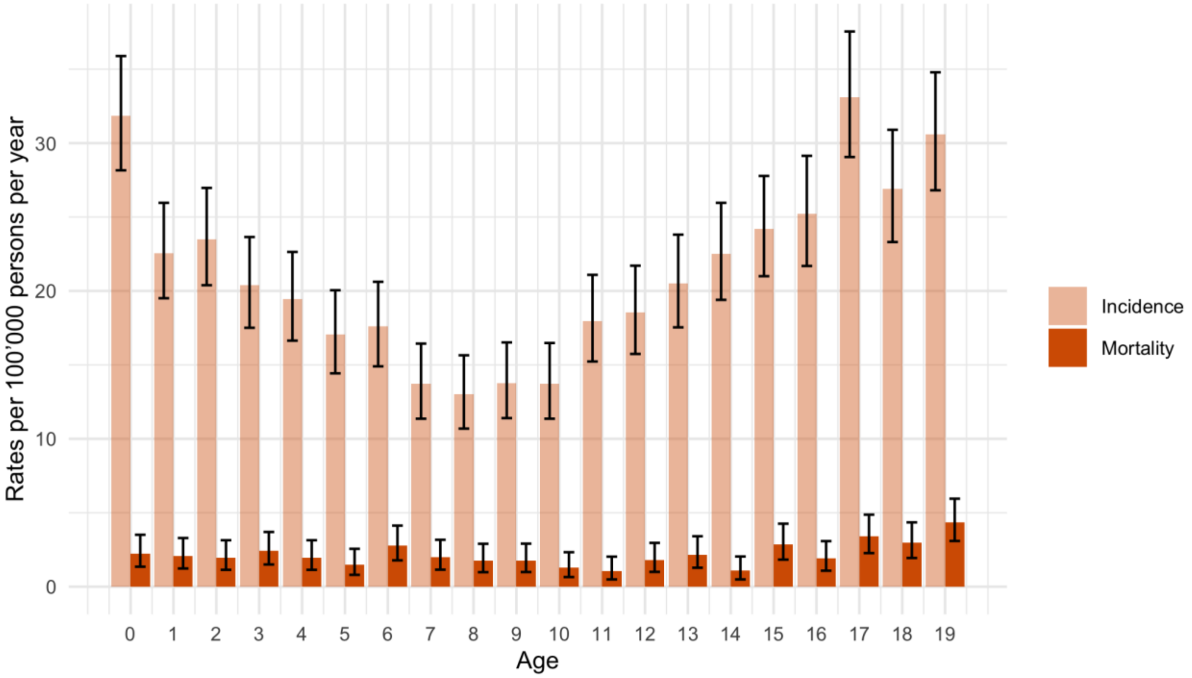
Types of cancer and new cases

The pattern of cancer types changes considerably during childhood and adolescence: In infants (under 1 year), embryonal tumours such as neuroblastomas are most common. In pre-school children, leukaemias predominate, while in school-aged children lymphomas and bone tumours become more frequent (G5.2). From the age of 10 onwards, the proportion of carcinomas and melanomas increases; these, along with lymphomas, leukaemias and germ cell tumours, are the most common cancer types in adolescents. CNS tumours make up a considerable share of cancers at all ages (G5.2).

G5.2 Proportions of ICCC-3 major groups and Langerhans cell histiocytosis by age at diagnosis, based on data from 2004 to 2023.



G5.3 Age-specific incidence and mortality in children and adolescents: rates per 100,000 person-years with 95% confidence intervals, based on data from 2014-2023.



In the period 2014-2023, the overall incidence rate for children (0-14 years) was 19 and for adolescents (15-19 years) 28 per 100,000 people per year (person-years). Incidence is relatively high in the first year of life, decreases throughout early childhood, and increases again after the age of 10 years (G5.3). The lowest age-specific incidence rate occurred at age 8, with 13 cases per 100,000 person-years. The highest incidence was observed in infants (<1 year) and at age 17 years, with 31.9 and 33.1 cases per 100,000 person-years, respectively (G5.3).

Figure G5.4 shows a slightly rising trend in incidence rates for both sexes since 2008. This increase could reflect an actual rise in incidence, improvements in cancer registration, but also improved diagnostics (e.g. in CNS tumours).

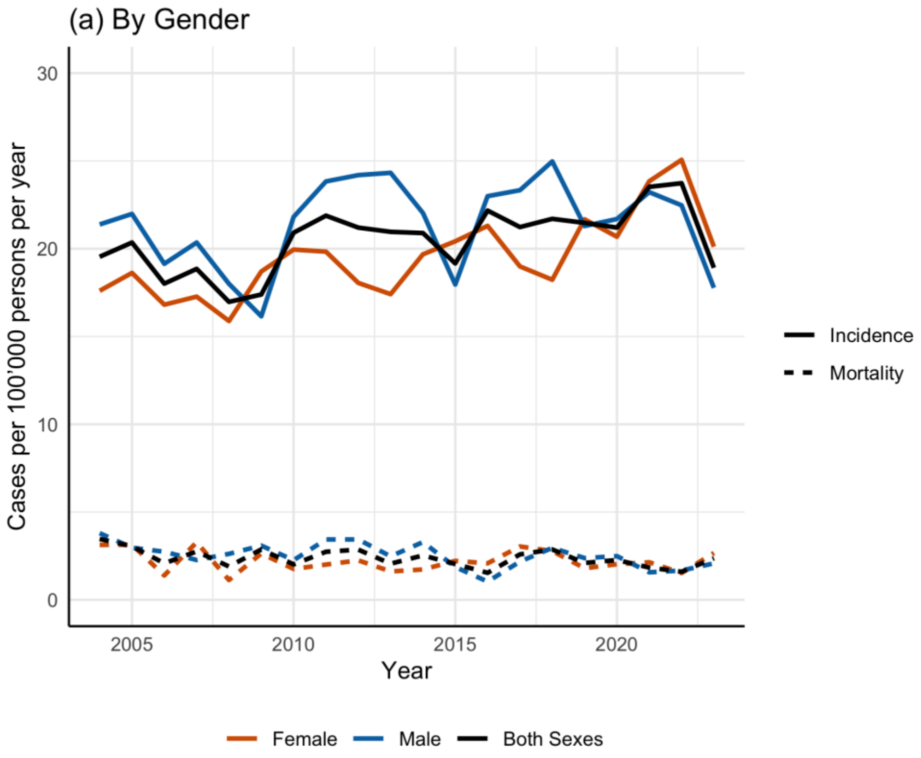
Tables T5.1-T5.2 show case numbers and incidence rates per 100,000 person-years for the period 2014-2023, broken down by cancer type, for children (T5.1: 0-14 years) and adolescents (T5.2: 15-19 years). Results for the combined age group (0-19 years) are provided in Appendix Table T13.1.

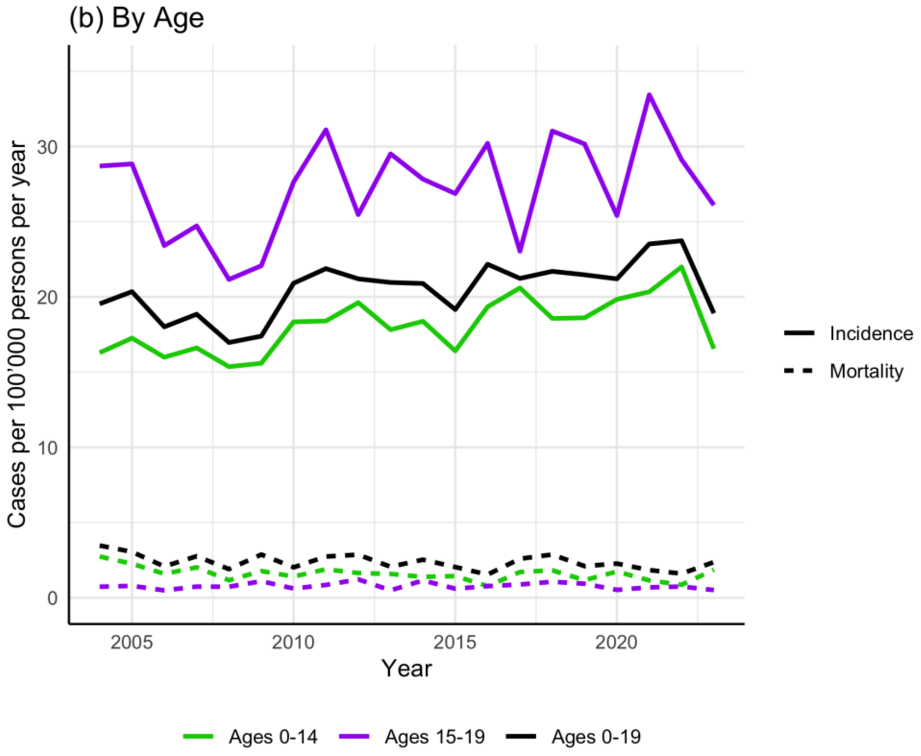
Mortality

Cancer is the second most common cause of death, after accidents, among children and adolescents. The mortality rate for the period 2014-2023 was 1.9 deaths per 100,000 person-years for children and 3.1 deaths per 100,000 person-years for adolescents. Mortality is relatively low during childhood but increases during adolescence (G5.3). Tables T5.3-T5.4 present cancer deaths according to ICCC-3 for the period 2014-2023, separately for children (T5.4: 0-14 years) and adolescents (T5.5: 15-19 years). Brain tumours and other CNS tumours are the most common causes of death in both age groups. Results for the combined age group (0-19 years) are provided in Appendix Table T13.2.

Looking at mortality over time from 2004 to 2023 (G5.4), a decreasing trend is evident, reflecting continuous improvements in therapy.

G5.4 Incidence and mortality in children (0-14 years) and adolescents (15-19 years) over time: crude rates per 100,000 person-years by sex (a) and age (b) based on data from 2004-2023.


(a) By Gender


(b) By Age

T5.1 Cancer cases in children (0-14 years), 2014-2023: Number of cases (n), relative frequency (%), crude incidence rate (per 100,000 person-years), median age at diagnosis in years, and sex ratio.

Cancer type		n	%	Incidence	Median age	Sex ratio (male:female)
I	**Leukaemia**	641	26	5.01	4	1.3
Ia	Lymphoid leukaemias	514		4.02	4	1.2
Ib	Acute myeloid leukaemias	72		0.56	3	1.3
II	**Lymphomas**	276	11	2.16	9.5	2.1
IIa	Hodgkin lymphomas	94		0.73	11	2
IIb	Non-Hodgkin lymphomas (except Burkitt lymphoma)	78		0.61	9	1.2
III	**Brain and other CNS tumours**	655	27	5.12	6	1
IIIa	Ependymomas and choroid plexus tumor	64		0.5	3	2.2
IIIb	Astrocytomas	239		1.87	6	0.9
IIIc	Intracranial and intraspinal embryonal tumours	105		0.82	4	1.1
IV	**Neuroblastoma**	144	6	1.13	1	1.1
V	**Retinoblastoma**	57	2	0.45	0	1.6
VI	**Kidney tumours**	119	5	0.93	3	0.9
VII	**Liver tumours**	37	2	0.29	2	1.2
VIII	**Bone tumours**	100	4	0.78	11.5	0.7
IX	**Soft tissue sarcomas**	135	6	1.06	5	0.8
X	**Germ cell tumours**	73	3	0.57	9	0.7
XI	**Other carcinomas and melanomas**	152	6	1.19	12	0.8
XII	**Other and unspecified neoplasms**	7	0	0.05	9	0.4
Total (excluding Langerhans cell histiocytosis)		2396	98	18.73	6	1.1
Langerhans cell histiocytosis		45	2	0.35	5	1.0
Total (including Langerhans cell histiocytosis)		2441	100	19.08	6	1.1

The table shows only the main groups and more common subgroups according to ICCC-3 and Langerhans cell histiocytosis. The total number differs from the sum of the subgroups, as not all subgroups are represented. Proportions are reported only for main ICCC-3 groups; subgroup cells are intentionally left blank

T5.2 Cancer cases in adolescents (15-19 years), 2014-2023: Number of projected cases (n), relative frequency (%), crude incidence rate (per 100,000 person-years), median age at diagnosis in years, and sex ratio.

Cancer type		n	%	Incidence	Median age	Sex ratio (male:female)
I	**Leukemias**	138	11	3.21	17	1.7
Ia	Lymphoid leukaemias	73		1.69	17	2.3
Ib	Acute myeloid leukaemias	28		0.66	17	1.3
II	**Lymphomas**	287	24	6.66	17	1.4
IIa	Hodgkin lymphomas	217		5.04	17	1.2
IIb	Non-Hodgkin lymphomas (except Burkitt lymphoma)	56		1.31	17	2.3
III	**Brain and other CNS tumours**	213	18	4.95	17	0.7
IIIa	Ependymomas and choroid plexus tumor	18		0.42	17	0.8
IIIb	Astrocytomas	62		1.43	17	0.6
IIIc	Intracranial and intraspinal embryonal tumours	15		0.34	18	1.1
IV	**Neuroblastoma**	10	1	0.24	17	0.3
V	**Retinoblastoma**	0	0	0		
VI	**Kidney tumours**	8	1	0.18	16	0.7
VII	**Liver tumours**	0	0	0		
VIII	**Bone tumours**	75	6	1.75	17	1.8
IX	**Soft tissue sarcomas**	65	5	1.51	17	1.6
X	**Germ cell tumours**	120	10	2.79	18	3.5
XI	**Other carcinomas and melanomas**	277	23	6.44	17	0.5
XII	**Other and unspecified neoplasms**	6	0	0.14	18	0.2
Total (excluding Langerhans cell histiocytosis)		1200	99	27.86	17	1.1
Langerhans cell histiocytosis		8	1	0.18	17	2.6
Total (including Langerhans cell histiocytosis)		1208	100	28.05	17	1.1

[1] NA: Values are either not calculable or not shown to prevent the disclosure of individual information. For example, if all cases with a particular diagnosis are of the same sex, the sex ratio will not be displayed.

The table shows only the main groups and more common subgroups according to ICCC-3 and Langerhans cell histiocytosis. The total number differs from the sum of the subgroups, as not all subgroups are represented. Proportions are reported only for main ICCC-3 groups; subgroup cells are intentionally left blank

T5.3 Cancer deaths in children (0-14 years), 2014-2023: Number of deaths (n), relative frequency (%), crude mortality rate (per 100,000 person-years), median age at death in years, and sex ratio.

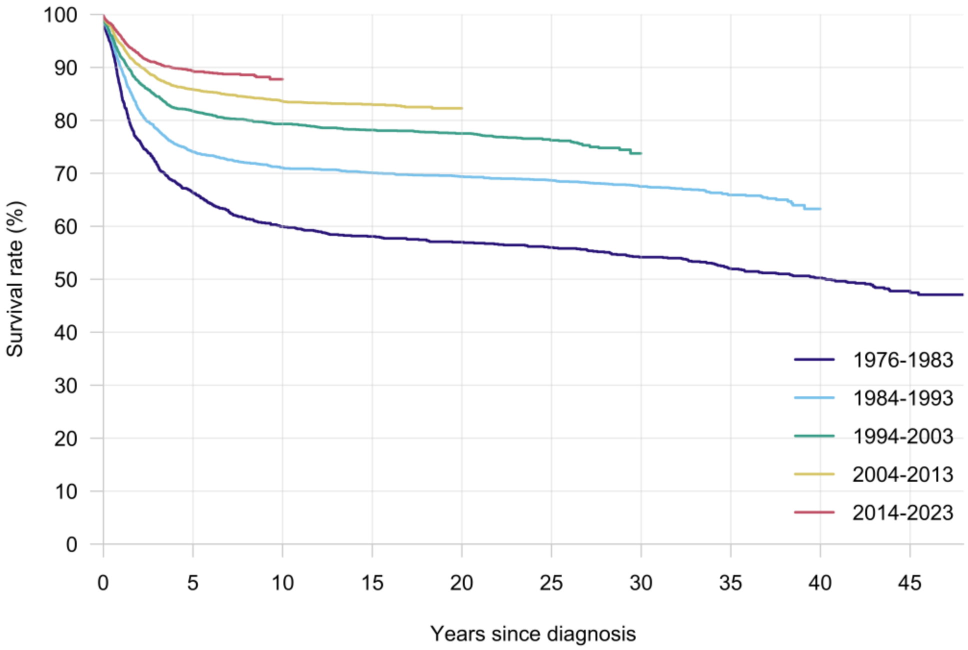
Cancer type		n	%	Mortality	Median age	Sex ratio (male:female)
I	Leukaemias	36	15	0.28	5	0.8
II	Lymphomas	7	3	0.05	12	2.5
III	Brain and other CNS tumours	125	53	0.98	6	1.2
IV	Neuroblastoma	16	7	0.13	3	0.6
V	Retinoblastoma	0	0	0	-	-
VI	Kidney tumours	6	3	0.05	1.5	2.0
VII	Liver tumours	5	2	0.04	5.5	1.5
VIII	Bone tumours	15	6	0.12	10.5	0.9
IX	Soft tissue sarcomas	20	8	0.16	6	0.5
X	Germ cell tumours	0	0	0	-	-
XI	Other carcinomas and melanomas	3	1	0.02	13	NA
XII	Other and unspecified neoplasms	5	2	0.04	9	1.5
Total		238	100	1.86	6	1.0

T5.4 Cancer deaths in adolescents (15-19 years), 2014-2023: Number of deaths (n), relative frequency (%), crude mortality rate (per 100,000 person-years), median age at death in years, and sex ratio.

Cancer type		n	%	Mortality	Median age	Sex ratio (male:female)
I	Leukaemia	21	16	0.49	18	1.3
II	Lymphomas	10	7	0.23	17	2.3
III	Brain and other CNS tumors	34	25	0.79	17	1.3
IV	Neuroblastoma	4	3	0.09	17.5	NA
V	Retinoblastoma	0	0	0	-	-
VI	Kidney tumours	2	1	0.05	16.5	NA
VII	Liver tumours	0	0	0	-	-
VIII	Bone tumours	27	20	0.63	17	0.8
IX	Soft tissue sarcomas	22	16	0.51	18	1.2
X	Germ cell tumours	3	2	0.07	19	-
XI	Other carcinomas and melanomas	6	4	0.14	19	NA
XII	Other and unspecified neoplasms	5	4	0.12	19	0.7
Total		134	100	3.11	17	1.1

[1] NA: Values are either not calculable or not shown to prevent the disclosure of individual information. For example, if all cases with a particular diagnosis are of the same sex, the sex ratio will not be displayed.

G5.5 Survival of children and adolescents by period of diagnosis: Survival rate over time following cancer diagnosis.



Survival

The survival rate following a childhood or adolescent cancer has improved significantly in recent decades (G5.5). The ten-year survival rate increased from 60% among children and adolescents diagnosed between 1976 and 1983, to 71% during the 1984-1993 period, 79% between 1994-2003, 84% between 2004-2013, and 88% in the 2014-2023 period (G5.5).

The long-term survival rate (10 years after cancer diagnosis) in the 2014-2023 period does not differ significantly between children and adolescents (G5.6). Female adolescents appear to have slightly higher survival chances than male adolescents (G5.6). This may be due to adolescent girls being more likely to develop cancers with a more favourable prognosis, such as thyroid cancer.

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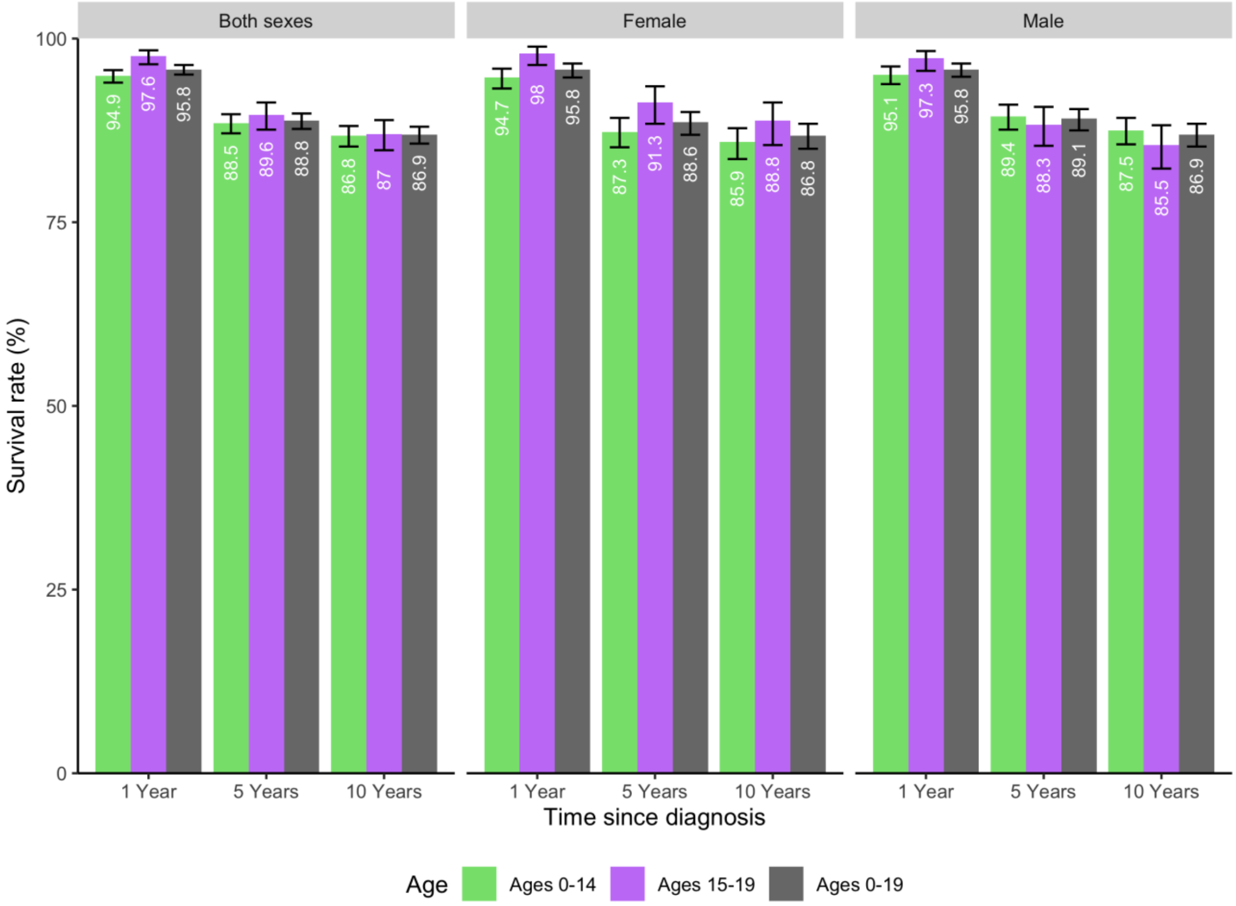
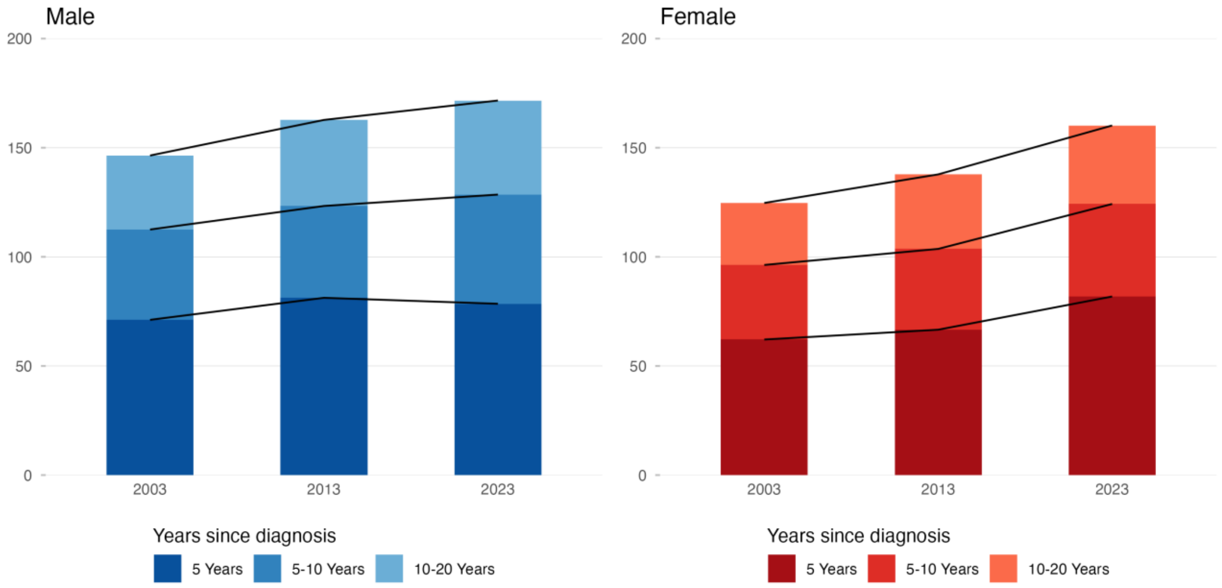
G5.6 One-, five-, and ten-year survival of children (0-14 years) and adolescents (15-19 years), presented separately and combined (0-19 years): Survival rates are shown overall and by sex, based on data from the 2014-2023 period. Error bars indicate 95% confidence intervals.



Number of affected individuals in the population

At the end of 2023, approximately 3,000 children and adolescents in Switzerland were living with a previous cancer diagnosis. This corresponds to 166 affected individuals per 100,000 people (prevalence rate for female children and adolescents: 160.2; for male children and adolescents: 171.6; G5.7). The analysis is limited to ages 0–19 because reliable estimates cannot be calculated for all age. Prevalence has increased in recent decades due to rising survival rates.

G5.7 Cancer prevalence in children and adolescents: Number per 100,000 individuals aged 0-19 years with a previous cancer diagnosis in the Swiss population.



6. Value of ChCR data

What is the value of data from the ChCR?

The ChCR supports the use of its data for research and evaluation purposes. Former patients may also request access to their data. This right is established under the Cancer Registration Act. The option to request data is widely used. In 2025 the ChCR received 24 enquiries from parents, authorities, former patients, patient organisations, physicians, and researchers. Below are some examples from recent years demonstrating how the data can be used.

For parents

A few years ago, the ChCR prepared a fact sheet on the care and nursing efforts provided by parents of a child with cancer, on behalf of the FOPH. The average loss of work for parents – based solely on the days spent in hospital with their sick child – was calculated at 155 days. This fact sheet served as one of the foundations for the new federal law aimed at improving the compatibility of employment and caring for relatives, which came into force in 2021. It provides carers with improved financial support and 14 weeks of paid carer leave per year, compared to just 3 days previously.

For former patients

The ChCR receives detailed information on diagnoses, examinations, and treatments from hospitals and laboratories, and stores this data in its database. Former patients can contact the ChCR at any time to request a copy of their data. This is particularly useful when precise information is required but can no longer be obtained from the hospital that previously provided treatment, which is unfortunately often the case. Such information is useful, for example, when planning repeat radiotherapy for a second tumour or for individualised screenings. Following certain therapies, it is advisable to begin screenings, such as colonoscopies or mammograms, at an earlier age than recommended for the general population.

For patient organizations

Patient organisations raise public awareness of the concerns of children affected by cancer and their families, but above all, they aim to support affected families with advice and practical assistance. To achieve this, they rely on key figures and data, such as the number of childhood cancer survivors currently living in Switzerland, the frequency of specific cancer diagnoses, and the risk of developing a second tumour. Information about current research findings based on ChCR data is also communicated to affected individuals and their families through the organisations.

For physicians

The ChCR is an important resource for physicians at SPOG clinics (those affiliated with the Swiss Paediatric Oncology Group), who can request data extracts on the number of newly diagnosed cancer cases or the number of patients participating in clinical trials. If a centre suspects a temporal or spatial clustering of new cancer cases, ChCR data can be used to assess whether this clustering is consistent with random variation or whether the region warrants closer monitoring. Upon request, the ChCR also provides physicians with comparative information on the number of cancer diagnoses treated or patient survival rates across different hospitals.

For researchers

The ChCR utilises the data to support a wide range of research projects. Supported projects include research into the causes of cancer in childhood and adolescence, investigations into the long-term effects of childhood cancer, and studies offering specific follow-up examinations for former patients. Specific examples of research based on ChCR data can be found in Chapter 7.

How can data be obtained from the ChCR?

For each data request, the ChCR requires the requesting person to provide information about the purpose and content of the requested data. Data request forms in German, English, French, and Italian can be downloaded from the ChCR website. Our website outlines the various data types available, noting that specific requirements must be fulfilled for delivery to be feasible and authorized, depending on the data requested. ChCR staff review all data requests against ethical and legal criteria, as well as the availability of the requested data in the database.

The ChCR provides patients' own data to them upon request. The ChCR verifies whether the person making the request is indeed the former patient or their legal representative. Identification with an official ID is required.

Statistical or aggregated data are data that do not permit any conclusions to be drawn about individual persons (e.g. the number of all new diagnoses in 2025 by cancer type). Such data are readily available and do not require an ethics application. Many important tables, graphs and statistics have already been published on our website and can be accessed directly there. However, additional analyses may be required.

When researchers require entire data sets, these can only be made available under very strict conditions. Treating oncology clinics can quickly obtain data on their own patients for evaluation purposes e.g., quality assurance, usually without ethics approval, as they already have access to this data in their hospital systems. Other requests require approval from the relevant ethics committee and must also comply with the strictest data protection measures. A contract governs data usage and ensures data protection. The ChCR is currently working on a solution to make data available anonymously on high-security servers, where it can be analysed but not downloaded.

International monitoring or benchmarking studies

The ChCR provides anonymised data for international collaborative studies:

- **CONCORD-4** is a programme led by the London School of Hygiene & Tropical Medicine to monitor global trends in cancer survival.
- The **European Network of Cancer Registries – European Cancer Information System (ENCR-ECIS)** regularly provides an overview of the cancer burden in individual European countries.
- The **Cancer Risk in Childhood Cancer Survivors (CRICCS)** project, based at the International Agency for Research on Cancer (IARC), investigates the risk of secondary cancers following childhood cancer.
- **International Benchmarking of Childhood Cancer Survival by Stage (BENCHISTA)** is a collaboration involving 70 cancer registries aimed at standardising and improving cancer registration.
- **EUROCARE** is a monitoring project that compares cancer incidence, survival trends, and treatment across European countries.

7. Latest developments in childhood cancer research

Thanks to research based on the collected data, new insights are gained each year. Here, we briefly present a selection of published findings from 2025. The references and the complete list of publications using ChCR data are provided in Chapter 10, Publications 2025.

Parental involvement in long-term follow-up care

This study (Baenziger et al. 2025) investigated the role of parents in the follow-up care of adult survivors in Switzerland. Based on data from the Swiss Childhood Cancer Registry, 466 parents were surveyed. One third of parents reported that their child attended follow-up care, whereas two thirds indicated that this was not the case. One in four parents had remained actively involved in follow-up care by providing medical and emotional support to their adult child. Mothers were more likely than fathers to motivate their children to attend appointments. Almost all (94%) of Swiss parents whose children attend follow-up were pleased with the care. Nearly 75% of parents of non-attenders did not feel follow-up was necessary, often because they considered their child to be "cured". The study suggests that parents could better encourage attendance if they are well informed about the possibilities and importance of lifelong monitoring.

Awareness of hearing loss after cancer treatment

This study (Jörger et al. 2025) assessed whether Swiss survivors are aware of their risk for hearing loss. Researchers surveyed 105 survivors treated with therapies that can damage the ear and cause hearing loss. Over half of study participants did not remember having been informed about this risk, and 30% could not remember having their hearing tested after therapy. Hearing tests showed significant hearing loss in 44% of the participants. The study highlights the need for cancer centres to educate survivors about potential late effects of ototoxic treatments to allow early diagnosis and treatment, particularly for those treated many years ago.

Exposure to ultraviolet radiation from the sun and the risk of childhood leukaemia

This study (Coste et al. 2025) investigated the link between solar ultraviolet radiation and childhood leukaemia and lymphoma in Switzerland. Using data from the Swiss National Cohort and the Childhood Cancer Registry, researchers analysed 1,446 cases. They found that children exposed to higher ultraviolet radiation, especially in July, had a decreased risk of developing acute lymphoblastic leukaemia (ALL). For every one-unit increase in the ultraviolet index, the risk decreased by 24%. No association was found for lymphoma. Similar findings had been reported in other studies. While the biological mechanisms are not fully understood, these results contribute to our understanding of environmental conditions in the causation of childhood cancer, perhaps via changes in immune mechanism or photosynthesis of vitamin D.

Long-term survival after leukaemia diagnosis – an international study

The Swiss Childhood Cancer Registry contributed data to this international study (Ssenyonga et al. 2025), which examined survival probabilities for over 120,000 children, adolescents, and young adults (ages 0-24 years) diagnosed with leukaemia from 61 countries. Switzerland was among the countries with highest survival among **children**. In these places, once a child had survived the first year, it had a 90% or higher chance to survive five years, and again a 90% or higher chance to be alive 10 years later. In Switzerland also **adolescents** reached 90% five years survival - a benchmark achieved by only seven countries globally. These results confirm that Switzerland achieves excellent and internationally very competitive results in treating cancer in children and adolescents.

8. Our partners

The ChCR collaborates closely with a range of stakeholders.

These include, primarily, the individuals and hospitals subject to reporting obligation, particularly the SPOG hospitals (hospitals affiliated with the Swiss Paediatric Oncology Group), which are responsible for treating childhood cancer patients and participate in clinical research to advance treatment options.

The ChCR also maintains close contact with patient and parent organisations, such as the umbrella organisation Childhood Cancer Switzerland (Kinderkrebs Schweiz, KKS) and various regional groups, including ARFEC (Association Romande des Familles d'Enfants atteints d'un Cancer), Childhood Cancer Aid Switzerland (Kinderkrebshilfe Schweiz), Childhood Cancer Aid Central Switzerland (Kinderkrebshilfe Zentralschweiz), and the Foundation for Children with Cancer, Regio Basiliensis (Stiftung für krebskranke Kinder, Regio Basiliensis) Regular meetings are held to exchange information and address the needs of affected families.

There is close cooperation with the Cantonal Cancer Registries for adult tumour diseases, the National Agency for Cancer Registry, and the FOPH. The ChCR also actively participates in the specialist groups responsible for implementing the Cancer Registration Act (CRA). There is also close cooperation with the FSO, both to ensure the completeness and quality of the data and to publish results on childhood cancer provided by the ChCR.

The ChCR also maintains active exchanges with other cancer registries, particularly the German Childhood Cancer Registry (Deutsches Kinderkrebsregister, DKKR).

As childhood cancer is a rare disease, international collaboration is particularly important to enable comparisons (benchmarking) and the creation of synergies. The ChCR is a member of the International Association of Cancer Registries (IACR) and the European Network of Cancer Registries (ENCR).

The ChCR also maintains numerous international collaborations and participates in global studies, as detailed in Chapter 6: the International Benchmarking of Childhood Cancer Survival by Stage (BENCHISTA) along with other projects of the European Network of Cancer Registries (ENCR), such as the European Cancer Information System (ECIS). It works with the Cancer Survival Group of the London School of Hygiene & Tropical Medicine, which conducts worldwide cancer survival studies (surveillance) on cancer (CONCORD); and of collaborates with international organisations led by the World Health Organisation (WHO), including the International Agency for Cancer Registration (IACR) and the International Agency for Research on Cancer (IARC).

9. Thanks from the heart

To collect data on cancer in children and adolescents, the ChCR relies on close collaboration with various institutions and stakeholders. We would like to take this opportunity to express our sincere thanks to all physicians, hospitals, pathology departments, and especially the SPOG member clinics (specialised treatment centres) and their clinical data managers. Successful childhood cancer registration is only possible through effective cooperation.

We also extend our sincere thanks to all patients who share their data with us, in appreciation of the trust they place in our work. Comprehensive data collection on cancer cases is essential for the continuous monitoring and accurate representation of the cancer situation in Switzerland.

Completeness, accuracy and timeliness of the data are vital for making a significant contribution to the improvement of cancer patient care.

Future developments

In 2025 the ChCR successfully managed the migration to NICERStat, the software also used by the Cantonal Registries for cancer cases in adults. Process adjustments and optimisations will be carried out during the year 2026, focusing on adaptations needed due to the new infrastructure.

In 2026 the ChCR is celebrating 50 years of childhood cancer registration in Switzerland with a two-day academic symposium. Experts from Switzerland and abroad will be speaking and discussing on topics such as cancer monitoring, clinical benefits, biobanking and molecular data, environmental medicine and patient-centred research. (Details to be found on the ChCR website News section.)

The ChCR is glad to contribute to the visionary project "Projekt Zielbild Krebsregistrierung in der Schweiz" and supports the development of a nationally efficient cancer registration system and processes that generate added value for all stakeholders involved. In particular, the ChCR supports all efforts towards digitalisation in the healthcare sector to make the work of reporting parties easier, decrease their workload, and ultimately make registry management more efficient.

In addition, in accordance with the decision of the Swiss Conference of Cantonal Health Directors (Gesundheitsdirektorenkonferenz, GDK), the ChCR will host the future Register of Highly Specialised Medicine in Paediatric Oncology. Implementation requires clarification of national vs cantonal responsibilities and therefore takes additional time in the coming years.

Impressum

Publisher: Childhood Cancer Registry,
Mittelstrasse 34, 3012 Bern,
www.childhoodcancerregistry.ch

10. 2025 publications based on ChCR data

Publications from previous years are available on the ChCR website.

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11. Abbreviations

ARFEC	Association Romande des Familles d'Enfants atteints d'un Cancer
Art.	Article
AYA	Adolescents and Young Adults 15–39 years
BENCHISTA	International Benchmarking of Childhood Cancer Survival by Stage https://www.ucl.ac.uk/child-health/research/developmental-biology-and-cancer/benchista-project
ChCR	National Childhood Cancer Registry of Switzerland since 2020
CNS	Central nervous system
CRA	Federal Act on the Registration of Cancer Diseases (Cancer Registration Act) https://www.fedlex.admin.ch/eli/cc/2018/289/de
CONCORD	Global surveillance on cancer survival of the Cancer Survival Group of the London School of Hygiene & Tropical Medicine https://csg.lshtm.ac.uk/research/themes/concord-programme/
CRICCS	Cancer Risk in Childhood Cancer Survivors https://criccs.iarc.who.int/
DKKR	German Childhood Cancer Registry / Deutsches Kinderkrebsregister
ECIS	European Cancer Information System https://ecis.jrc.ec.europa.eu/
ENCR	European Network of Cancer Registries
EUROCARE	EUROpean CAncer REgistry based study on survival and care of cancer patients (monitoring project to compare cancer incidence, survival trends, and cancer treatment between European countries)
FOPH	Federal Office of Public Health
FSO	Federal Statistical Office
GBE / HRC	Health Reporting on Cancer (Gesundheitsberichterstattung, GBE)
GDK	Swiss Conference of Cantonal Health Directors (Gesundheitsdirektorenkonferenz, GDK)
IACR	International Association of Cancer Registries
IARC	International Agency for Research on Cancer
ICCC-3	International Classification of Childhood Cancer, Version 3.0
ICD	International Classification of Diseases
ICD-O	International Classification of Diseases of Oncology
ISPM	Institute for Social and Preventive Medicine
KKS	Childhood Cancer Switzerland / Kinderkrebs Schweiz
NACR	National Agency for Cancer Registration

Para.	Paragraph
RCD	Department of Registration, Coding and Data Quality of the ChCR
SCCR	Swiss Childhood Cancer Registry till end of 2019
SPOG	Swiss Paediatric Oncology Group
WHO	World Health Organisation

12. Definitions / glossary

Waiting period	The Federal Council has established a three-month waiting period, during which cancer registries must delay registering data that have already been submitted. This allows patients sufficient time to decide whether to exercise their right to object. Data are only recorded in the Childhood Cancer Registry if no objection has been received after this period has expired (Art. 6 para. 1 CRA); see information brochure for patients, page 17.
Initial diagnosis	First diagnosis of cancer, standardised to the date of tissue or cell sampling
Incidence	Frequency of new cases: Incidence is the number of newly occurring cases of disease within a defined group in a certain period of time.
Date of diagnosis	The diagnosis or incidence date corresponds to the date of initial diagnosis in patients.
Year of diagnosis	Year of onset of a disease (incidence year)
Relevant cases	Relevant cases for the Childhood Cancer Registry are cancers in children and adolescents under 20 years of age, as defined by the CRA and the list of notifiable cancers in Appendix 1, CRO. The Swiss cancer registries are population-based: they record cases occurring in the Swiss population (residence of ≥12 months) and among individuals residing in Switzerland at the time of diagnosis.

13. Appendix Results

T13.1 Cancer cases in children and adolescents (0-19 years), 2014-2023: Number of projected cases (n), relative frequency (%), crude incidence rate (per 100,000 person-years), median age at diagnosis in years, and sex ratio.

Cancer type		n	%	Incidence	Median age	Sex ratio (male:female)
I	**Leukaemias**	779	21	4.56	6	1.3
Ia	Lymphoid leukaemias	587		3.43	5	1.3
Ib	Acute myeloid leukaemias	100		0.59	9	1.3
II	**Lymphomas**	563	15	3.29	14	1.7
IIa	Hodgkin lymphomas	311		1.82	16	1.4
IIb	Non-Hodgkin lymphomas (except Burkitt lymphoma)	134		0.79	13	1.6
III	**Brain and other CNS tumours**	868	24	5.08	9	0.9
IIIa	Ependymomas and choroid plexus tumour	82		0.48	5.5	1.7
IIIb	Astrocytomas	301		1.76	8	0.9
IIIc	Intracranial and intraspinal embryonal tumors	120		0.7	5	1.1
IV	**Neuroblastoma**	154	4	0.9	1	1.1
V	**Retinoblastoma**	57	2	0.33	0	1.6
VI	**Kidney tumours**	127	3	0.74	3	0.9
VII	**Liver tumours**	37	1	0.22	2	1.2
VIII	**Bone tumours**	175	5	1.03	13	1
IX	**Soft tissue sarcomas**	200	5	1.17	10	1
X	**Germ cell tumours**	193	5	1.13	16	1.8
XI	**Other carcinomas and melanomas**	429	12	2.51	16	0.6
XII	**Other and unspecified neoplasms**	13	0	0.07	13.5	0.3
Total (excluding Langerhans cell histiocytosis)		3596	99	21.03	10	1.1
Langerhans cell histiocytosis		53	1	0.31	7	1.1
Total (including Langerhans cell histiocytosis)		3649	100	21.34	10	1.1

The table shows only the main groups and more common subgroups according to ICCC-3 and Langerhans cell histiocytosis. The total number differs from the sum of the subgroups, as not all subgroups are represented. Proportions are reported only for main ICCC-3 groups; subgroup cells are intentionally left blank

T13.2 Cancer deaths in children and adolescents (0-19 years), 2014-2023: Number of deaths (n), relative frequency (%), crude mortality rate (per 100,000 person-years), median age at death in years, and sex ratio.

Cancer type		n	%	Mortality	Median age	Sex ratio (male:female)
I	Leukaemias	57	15	0.33	10	1.0
II	Lymphomas	17	5	0.1	16	2.4
III	Brain and other CNS tumors	159	43	0.93	8	1.2
IV	Neuroblastoma	20	5	0.12	6.5	0.4
V	Retinoblastoma	0	0	0	-	-
VI	Kidney tumours	8	2	0.05	4.5	1.7
VII	Liver tumours	5	1	0.03	5.5	1.5
VIII	Bone tumours	42	11	0.25	15	0.8
IX	Soft tissue sarcomas	42	11	0.25	15	0.8
X	Germ cell tumours	3	1	0.02	19	-
XI	Other carcinomas and melanomas	9	2	0.05	18	0.5
XII	Other and unspecified neoplasms	10	3	0.06	15	1.0
Total		372	100	2.18	11	1.0

[1] **NA:** Values are either not calculable or not shown to prevent the disclosure of individual information. For example, if all cases with a particular diagnosis are of the same sex, the sex ratio will not be displayed.