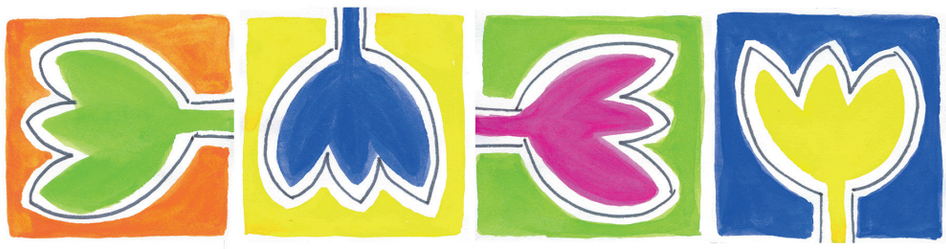
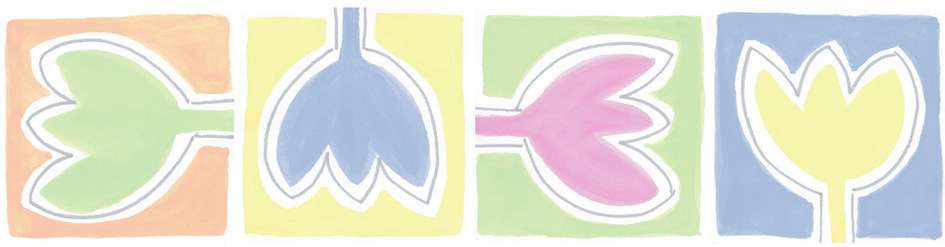
swiss childhood cancer registry



annual report 2014 - 2015

Swiss Childhood Cancer Registry
Annual Report 2014/2015



For the Swiss Childhood Cancer Registry

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Bern, Swiss Childhood Cancer Registry

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Table of contents

1. Introduction

The Swiss Childhood Cancer Registry (SCCR) is the national population-based cancer registry for children and adolescents in Switzerland. New cancer diagnoses, clinical information, details on treatment and long-term follow-up (survival, second primary neoplasms and late effects) have been registered in the SCCR since 1976. **This year, 2016, the SCCR celebrates its 40th birthday!** With many associated research projects and through close collaboration with clinicians it contributes to understanding the causes of cancer in children, improving follow-up care and reducing late effects.

The SCCR is located at the Institute of Social and Preventive Medicine (ISPM) at the University of Bern. It is operated jointly by the Swiss Paediatric Oncology Group (SPOG) and the University of Bern. Since 1976, all nine Swiss paediatric haematology-oncology centres report newly diagnosed cases to the registry and send annual updates on clinical follow-up. Since 2007, the SCCR also collects supplementary data from other sources, including cantonal cancer registries, other hospitals, pathology laboratories and the Swiss Federal Statistical Office (SFSO). As of 31st December 2014, data from 9353 cases (diagnosed in 9225 patients) have been registered.

The SCCR is authorized to collect non-anonymised data. The permission has been issued in 2007 by the Federal Commission of Experts for Professional Secrecy in Medical Research (Eidgenössische Expertenkommission für das Berufsgeheimnis in der medizinischen Forschung). Since 2014 the new act on human research is in place. The SCCR got a new authorization issued by the ethics committee of the canton of Bern in July 2014.

The SCCR is an associated member of the National Institute for Cancer Epidemiology and Registration (NICER), of the European Network of Cancer Registries (ENCR) and of the International Association of Cancer Registries (IACR), and collaborates with childhood cancer registries throughout Europe.

What did the Swiss Childhood Cancer Registry achieve in 40 years?

- Performed national childhood cancer monitoring of high quality
- Provided reliable statistical routine data
- Established a competitive research platform
- Gave competent ad hoc answers to health-, environmental-, socio-, political-related questions
- Cooperated closely with all paediatric oncologists,
- Established a strong network with Swiss parents organisations

This seventh report covers the routine analyses of all children diagnosed between 1st January 1976 and 31st December 2014. Activities, research and publications of the SCCR are described for the years 2014 to 2016. The report contains:

- An overview of the organisation and team of the SCCR, SPOG and the participating paediatric haematology-oncology centres **(Chapter 2)**
- A summary of the data collected in the registry up to 31st December 2014 **(Chapter 3)**
- A summary of current research of the SCCR **(Chapter 4)**
- A list of publications **(Chapter 5)**

Our website (www.childhoodcancerregistry.ch) contains further information, including past annual reports and scientific publications.

We would like to thank all the children and their families, and all adolescent and adult childhood cancer survivors, for allowing us to collect their data. We also thank the physicians and clinical research coordinators of the Swiss Paediatric Oncology Group for their excellent collaboration. Our thanks also go to the cantonal cancer registries, the National Institute for Cancer Epidemiology and Registration (NICER), the Swiss Federal Statistical Office (SFSO), the Federal Office of Public Health (FOPH) and the pathology laboratories for their cooperation. Finally, we thank our supporters for their generous contributions.

2. Organisation of the Swiss Childhood Cancer Registry

The Swiss Childhood Cancer Registry (SCCR) is a member of the Swiss Paediatric Oncology Group (SPOG) and is organised as a joint operation of the Institute of Social and Preventive Medicine (ISPM) at the University of Bern and the SPOG.

2.1 Institute of Social and Preventive Medicine (ISPM), University of Bern

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Parvinder Singh	Statistics	
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Trust Centre	
Christina Krenger	Data management

Informatics and database support	
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2.2 Swiss Paediatric Oncology Group (SPOG)

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Heinz Hengartner, MD	Vice president	
Maja Beck Popovic, Prof MD	Committee Member	

SPOG Office in Bern		
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Julia Ruckstuhl, MSc	Head Regulatory affairs	
Tu-My Diep Lai, PhD	Regulatory affairs	
Martina Peluso, MSc	Regulatory affairs	
Silvia Wirth, PhD	Quality assurance Regulatory affairs	

Participating centres (paediatric haematology-oncology)	Head of Division	Clinical Research Coordinator
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Bern Universitätsklinik für Kinderheilkunde, Inselspital	K. Leibundgut, Prof MD	F. Julmy N. Beusch
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2.3 General information

Aims

The Swiss Childhood Cancer Registry collects information on the diagnosis, treatment and follow-up of children and adolescents with cancer in Switzerland, and provides data for national and international statistics and research projects.

It aims:

- To collect representative, population-based data on cancer in children and adolescents in Switzerland (cancer incidence, prevalence, time trends, regional distribution and survival rates)
- To document diagnostic evaluations, treatment and participation in clinical trials
- To describe short-term and long-term prognosis (mortality, morbidity and quality of life) after cancer in childhood and adolescence
- To provide a research platform for clinical, epidemiological and basic research

It thus contributes to:

- Research into the aetiology of cancer in children and adolescents
- Planning of health services
- Continuous improvement of treatment
- Identifying possible late effects of therapy, with the aim to diagnose and treat them early and prevent them in the future

Inclusion criteria

The SCCR registers all children and adolescents aged 0 to 20 years, resident or treated in Switzerland, diagnosed with:

- Acute and chronic leukaemias, including myelodysplastic syndrome
- Lymphomas
- Malignant solid tumours
- Central nervous system tumours (CNS), malignant and benign tumours
- Langerhans cell histiocytosis (LCH), Hemophagocytic lymphohistiocytosis (HLH)

Since 2014 it also registers children and adolescents diagnosed with:

- Aggressive fibromatosis (ICD-O-3M code 8821/1)
- Benign/mature teratoma (ICD-O-3M code 9080/0)
- Mesoblastic nephroma (ICD-O-3M code 8960/1)
- Severe aplastic anaemia (ICD-10 D61.9)
- Neoplasms of the liver, histologically proven, but no malformations

Children and adolescents who are not Swiss residents but are diagnosed or treated in Switzerland are registered, but they are excluded from analyses of incidence and survival.

Sources of data

Data on children and adolescents with cancer are collected from several sources, including:

- The nine Swiss centres for paediatric oncology and haematology (**Chapter 2.2**)
- Other hospitals
- Cantonal cancer registries, represented by the National Institute for Cancer Epidemiology and Registration (NICER)
- Clinical and epidemiological registries (e.g. brain tumour registry, bone tumour registry, Swiss growth registry etc.)
- The Swiss Federal Statistical Office (SFSO; Swiss mortality statistics)
- Pathology laboratories

Most children are reported by one of the nine Swiss centres for paediatric oncology and haematology. Local clinical research coordinators complete forms for all newly diagnosed patients. Basic information on diagnosis is later completed with information on treatments, remissions, relapses, transplantations and health outcomes. These forms are sent to the SCCR and information is entered into the database. Important medical documents (e.g. pathology reports) are scanned and stored electronically using a pseudonym. Paper copies are destroyed. Information on Swiss residency is validated through municipal population registers.

For the first five to ten years after diagnosis follow-up data is extracted annually from patients' hospital records by the local clinical research coordinators in all paediatric oncology and haematology centres (**Chapter 3.3**). To assess outcomes after the children have left the clinic, patients are contacted directly with a questionnaire and data is linked to mortality records (SFSO) and to records from cantonal cancer registries (**Chapter 4.2**). Life status update is assessed through community registries. For children not treated in a paediatric oncology and haematology centre, clinical follow-up from hospitals is often not available, but long-term epidemiological follow-up is done via questionnaires and by assessment of second primary neoplasms and mortality as for the other patients and life status update via community registries (**Chapter 3.3**).

Clinical database

The current SCCR database was set up in 2007. The following information is routinely collected:

- Tumour diagnosis, date of diagnosis, morphology, topography, stage, metastases
- Other diagnoses (cancer-relevant pre-existing conditions)
- Relevant laboratory and clinical data
- Treatment (clinical trial participation, chemotherapy, radiotherapy, surgical intervention, bone marrow transplantation) and treatment centres involved
- Follow-up data (changes of treatment, remissions, relapses, survival/death and cause of death)
- Late adverse outcomes (e.g. cardiovascular diseases, second primary neoplasms and endocrine disorders)

Trust centre

Since 2010, personal information (name and address) is stored in a separate database in the trust centre. The trust centre validates addresses, residence status, nationality, and vital status via community registers. This personal information is separated strictly from clinical information of the SCCR database. The following data is collected:

- Patient name, address of residence at time of diagnosis, current address of residence
- Date of birth, sex, first language
- Country of residence and nationality at time of diagnosis
- Vital status and date of death
- Parental profession, parental date of birth

Tumour coding

All tumours are coded according to the following international classification systems (see appendix):

- International Classification of Childhood Cancer, third edition (ICCC-3)
- International Classification of Diseases for Oncology, third edition (ICD-O-3)
- International Classification of Diseases and Related Health Problems, tenth revision (ICD-10)

In the annual report, the main diagnostic groups of the ICCC-3 are used:

I. Leukaemias, myeloproliferative diseases, and myelodysplastic diseases
II. Lymphomas and reticuloendothelial neoplasms
III. CNS and miscellaneous intracranial and intraspinal neoplasms
IV. Neuroblastoma and other peripheral nervous cell tumours
V. Retinoblastoma
VI. Renal tumours
VII. Hepatic tumours
VIII. Malignant bone tumours
IX. Soft tissue and other extraosseous sarcomas
X. Germ cell tumours, trophoblastic tumours, and neoplasms of gonads
XI. Other malignant epithelial neoplasms and malignant melanomas
XII. Other specified and unspecified malignant neoplasms

Langerhans cell histiocytosis (LCH), which is not included in ICCC-3, is reported separately.

Data protection

In 2004, the SCCR received a special authorisation (Sonderbewilligung) from the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research. Starting from June 2007, a general authorization (Registerbewilligung)) permitted the data collection from paediatric cancer patients (children and adolescents) throughout Switzerland after obtaining written, oral or silent consent.

Since January 2014 the new Human Research Act and its three ordinances are in place. Out of those three ordinances, the ordinance on Human Research with the exception of Clinical Trials provides the new framework for the SCCR. Instead of the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research, data collection and storage by SCCR now require an authorisation by the ethics committee of the canton of Bern. The general authorization (Registerbewilligung) has been replaced in July 2014 by an approval from the ethics committee of the canton of Bern.

Funding

The SCCR thanks the following supporters for their financial contributions towards the daily operation and the continuous development of the registry. Supporters of scientific research of the SCCR are listed in **Chapter 4**.

Main funding sources 2014/2015

- Schweizerische Konferenz der kantonalen Gesundheitsdirektoren und -direktorinnen (GDK)
- Schweizerische Pädiatrische Onkologie Gruppe (SPOG)
- Universität Bern, Institut für Sozial- und Präventivmedizin (ISPM)
- Krebsforschung Schweiz
- Kinderkrebshilfe Schweiz

Other funding sources 2014/2015

- National Institute for Cancer Epidemiology and Registration (NICER)
- Federal Office of Health (FOH)
- AXA-Winterthur
- Celgene GmbH
  (through Förderverein Schweizer Kinderkrebsregister)
- Amgen Switzerland AG
  (through Förderverein Schweizer Kinderkrebsregister)
- Helsana Versicherungen AG
  (through Förderverein Schweizer Kinderkrebsregister)

3. Routine Analyses

3.1 Overview

The SCCR registers all tumours diagnosed and treated in Switzerland, classified according to the ICCC-3 and Langerhans cell histiocytosis (LCH) in patients aged 0 to 20 years at time of diagnosis. This annual report covers the time period from 1st January 1976 until 31st December 2014. The additional disorders, which are registered since 2014 (see inclusion criteria under paragraph 2.3), have not been included in the following analyses. Incidence rates are calculated based on the number of primary neoplasms (cases). The number of cases slightly exceeds the number of patients because patients with more than one primary tumour diagnosed before age 20 years are counted separately for each new tumour.

The section on routine analyses includes three chapters:

Chapter 3.2 presents data on all cases registered in the SCCR. This includes cases resident in Switzerland or abroad, who were diagnosed or treated in Switzerland.

Chapter 3.3 presents data on cases resident in Switzerland, aged 0 to 14 years at diagnosis. This correspondents to the age group usually covered in international publications. Therefore, tables and figures can be compared with data from other countries. Because registration in Switzerland is more than 95% complete for this age range with estimated incidence and survival rates close to their true value.

Chapter 3.4 presents data on cases resident in Switzerland, aged 15 to 20 years at diagnosis. Patients of this age group are treated in a large number and variety of clinics and therefore registration is less complete. Ultimately, incidence rates cannot be calculated for this age group.

3.2 All cases registered in the SCCR (N=9353)

This chapter describes data from all cases diagnosed 1976-2014, resident in Switzerland or abroad, diagnosed or treated in Switzerland (N=9353).

Up to 31st December 2014, a total of 9353 cases classifiable according to the ICCC-3, or Langerhans cell histiocytosis (LCH), have been registered in the SCCR. These tumours were diagnosed in 9225 patients. Among these, 9099 patients had only one primary neoplasm, 124 patients had two primary neoplasms and 2 patients had three primary neoplasms at age 0-20 years.

The SCCR started in 1976. Initially, only patients aged 0 to 15 years who participated in clinical trials were registered. Non-trial patients have been included since 1982, resulting in a significant increase in the number registered. In the early 1990s, the introduction of the first electronic database further increased case registration. Since then, annual registration has remained constant (**Figure 1**).

In the last five years (2010-2014), a total of 1461 newly diagnosed cases were registered; among them 1278 cases in Swiss residents (**Table 1**).

Swiss residents account for 8317 (89%) of all cases and foreign residents for 1036 (11%) cases (**Table 2**). Swiss residents make up 38% (168/447) of all retinoblastoma patients, while foreign residents make up 62% (279/447) of these patients. This is due to the international reputation of the Jules Gonin Hospital in Lausanne, which is the national centre for retinoblastoma treatment but also attracts many patients from abroad.

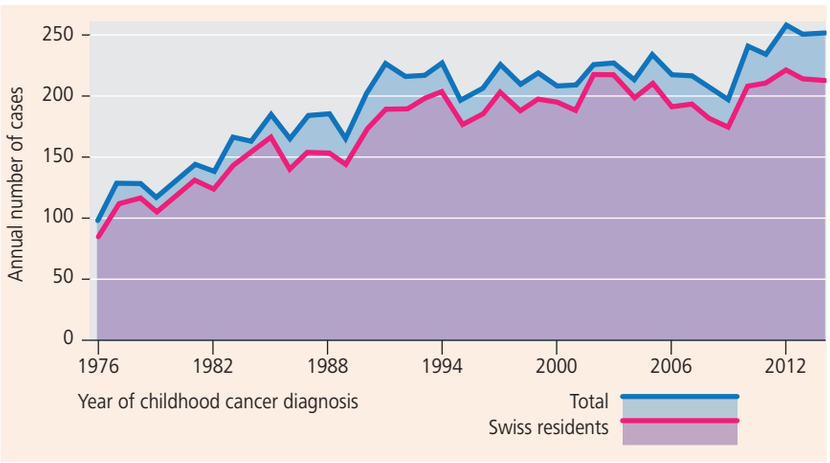


Figure 1
Annual number of registered cases over time
Swiss and foreign residents, age at diagnosis 0-14 years; period of diagnosis 1976-2014; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=7504

Table 1
Total number of cases registered in the SCCR, by period of diagnosis

	All patients residents		Swiss residents		Foreign	
Year of diagnosis	Age at diagnosis (years)		Age at diagnosis (years)		Age at diagnosis (years)	
	0-14	15-20	0-14	15-20	0-14	15-20
1976-1984	1151	267	1024	243	127	24
1985-1989	864	231	730	213	134	18
1990-1994	1080	253	934	231	146	22
1995-1999	1043	294	930	268	113	26
2000-2004	1072	279	999	257	73	22
2005-2009	1061	297	931	279	130	18
2010-2014	1233	228	1056	222	177	6
	7504	**1849**	**6604**	**1713**	**900**	**136**

Swiss and foreign residents, age at diagnosis 0-20 years; period of diagnosis 1976-2014; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=9353

Table 2
Total number of cases registered in the SCCR, by country of residence

	Age at diagnosis (years)					
	All ages (0-20)		Children (0-14)		Adolescents (15-20)	
Country of residence	n	%	n	%	n	%
Switzerland	8317	88,9	6604	88,0	1713	92,6
Foreign countries	1036	11,1	900	12,0	136	7,4
Europe	726	7,8	645	8,6	81	4,4
• Neighbouring countries	405	4,3	351	4,7	54	2,9
- Austria	10	0,1	10	0,1	0	0,0
- France	141	1,5	110	1,5	31	1,7
- Germany	79	0,8	74	1,0	5	0,3
- Italy	174	1,9	156	2,1	18	1,0
- Liechtenstein	1	0,0	1	0,0	0	0,0
• Other European countries	321	3,4	294	3,9	27	1,5
Middle East	34	0,4	29	0,4	5	0,3
North Africa	152	1,6	122	1,6	30	1,6
Other African countries	48	0,5	41	0,5	7	0,4
All other countries	59	0,6	51	0,7	8	0,4
Abroad	17	0,2	12	0,2	5	0,3
TOTAL	**9353**	**100,0**	**7504**	**100,0**	**1849**	**100,0**

Swiss and foreign residents, age at diagnosis 0-20 years; period of diagnosis 1976-2013; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=9353

3.3 Swiss residents aged 0-14 years at diagnosis (N=6604)

This chapter reports on cases aged 0-14 years and resident in Switzerland at diagnosis with a tumour coded according to ICCC-3 or a Langerhans cell histiocytosis. Results for this age group can be compared directly to data from other countries.

Diagnoses

The International Classification of Childhood Cancer (ICCC-3) distinguishes 12 groups of cancers (**Table 3**). The most common are leukaemias (33% of all cancers), followed by tumours of the central nervous system (20%; especially brain tumours); and lymphomas (12%). Other cancers arise from embryonic tissue. These include neuroblastoma (7%) from primitive neural tissue, nephroblastoma (5%) from renal tissue, hepatoblastoma (1%) in the liver, germ cell tumours (3%), and retinoblastoma (3%).

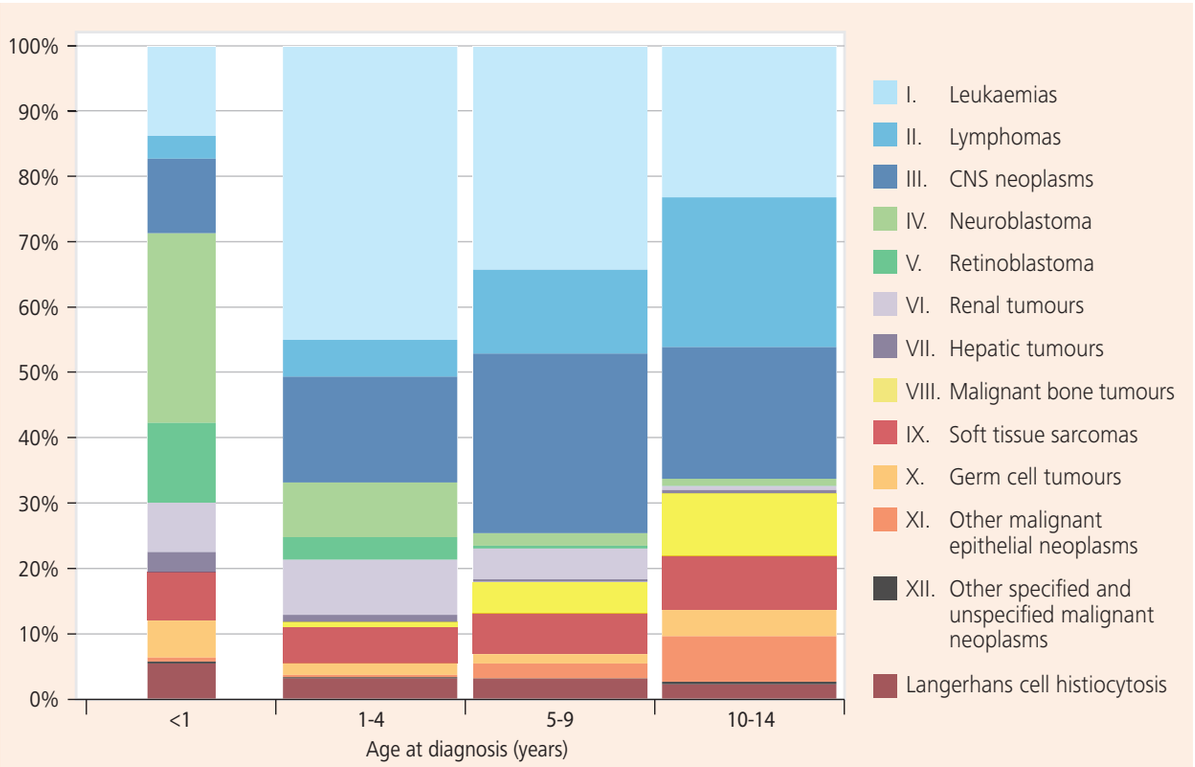
Germ cell tumours may arise in the gonads (ovaries and testes), or in other sites, such as the brain (intracranial germ cell tumours). Soft tissue sarcomas (7%), and malignant bone tumours (4%) arise from abnormal connective tissue. Occasionally, children also develop carcinomas such as melanomas or other rare tumours (3%). Langerhans cell histiocytosis (3%) is officially not counted as a malignant disease. But as children with this disease are treated similarly to those with cancer and in rare cases also die, they are recorded in the Swiss Childhood Cancer Registry. The relative frequency of the different tumour types varies with age (**Table 3** and **Figure 2**).

Table 3 Main diagnostic groups according to ICCC-3, by age at diagnosis

		All children		By age at diagnosis (years)							
				<1		1-4		5-9		10-14	
Diagnosis		n	%	n	%	n	%	n	%	n	%
I	Leukaemias, myeloproliferative diseases and myelodysplastic diseases	2167	32,8	87	13,7	1039	45,0	605	34,2	436	23,1
II	Lymphomas and reticuloendothelial neoplasms	814	12,3	22	3,5	130	5,6	228	12,9	434	23,0
III	Central nervous system neoplasms	1318	20,0	73	11,5	375	16,2	488	27,6	382	20,2
IV	Neuroblastoma and other peripheral nervous cell tumours	432	6,5	185	29,1	194	8,4	34	1,9	19	1,0
V	Retinoblastoma	167	2,5	78	12,3	80	3,5	8	0,5	1	0,1
VI	Renal tumours	339	5,1	48	7,5	196	8,5	83	4,7	12	0,6
VII	Hepatic tumours	62	0,9	20	3,1	25	1,1	7	0,4	10	0,5
VIII	Malignant bone tumours	285	4,3	0	0,0	19	0,8	86	4,9	180	9,5
IX	Soft tissue and other extraosseous sarcomas	443	6,7	47	7,4	127	5,5	111	6,3	158	8,4
X	Germ cell tumours, trophoblastic tumours and neoplasms of gonads	179	2,7	36	5,7	42	1,8	25	1,4	76	4,0
XI	Other malignant epithelial neoplasms and malignant melanomas	184	2,8	4	0,6	8	0,3	40	2,3	132	7,0
XII	Other specified and unspecified malignant neoplasms	14	0,2	2	0,3	4	0,2	1	0,1	7	0,4
	Langerhans cell histiocytosis	200	3,0	34	5,3	71	3,1	54	3,1	41	2,2
	Total	**6604**	**100,0**	**636**	**100,0**	**2310**	**100,0**	**1770**	**100,0**	**1888**	**100,0**

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1976-2014; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=6604

Figure 2
Main diagnostic groups according to ICCC-3, by age at diagnosis



Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1976-2014; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N = 6604

Follow-up information

The SCCR collects follow-up information for patients in several ways:

1. **Clinical follow-up** is any contact the patient has with the paediatric oncology and haematology centre. Annual clinical follow-up care in paediatric centres usually ends 5-10 years after diagnosis. Then the patient is officially discharged or referred to an adult oncology centre. Alternatively clinical follow-up also ends as soon as the patient dies.
2. **Long-term epidemiological follow-up** for vital status, subsequent neoplasms and current health employs four complementary approaches:
   - **Vital status** and **current address** and place of birth are updated by contacting municipal population registers. Vital status is known for most cases: among the 6541 patients, 1636 (25%) have died, and 4905 (75%) are still alive (**Table 4**). Among these, most (4608) have been followed-up during the past 5 years, 165 (3%) have last been followed up between 2004 and 2008, and only 132 (3%) before 2004. Among the latter, 93 (32 between 2004-2008 and 61 before 2004) are lost to follow-up, because they moved abroad.
   - **Causes of death** are retrieved from Swiss mortality statistics by record linkage.
   - **Second primary neoplasms** are notified via paediatric oncology and haematology centres, detected by regular comparison with cantonal (regional) cancer registries in Switzerland, or self-reported by survivors and then validated with pathology reports.
   - **Morbidity and quality of life** are assessed by paper questionnaires to survivors in the Swiss Childhood Cancer Survivor Study and Childhood Cancer Follow-up Study (**Chapter 4.2**).

Table 4
Follow-up information available in the SCCR

	n	%
Alive	**4905**	**75.0**
Last clinical follow-up after 2008	4608	93.9
Last clinical follow-up 2004-2008	165	3.4
Last clinical follow-up before 2004	132	2.7
Deceased	**1636**	**25.0**
TOTAL	**6541**	**100.0**

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1976-2014; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=6541 patients (6604 cases)

Survival

Long-term survival has improved significantly over the last decades (**Figure 3**).

Ten-year survival increased from 58% in children diagnosed between 1976 and 1984, to 71% in children diagnosed between 1985 and 1994, 80% in children diagnosed between 1995 and 2004, and 87% in children diagnosed within the last decade (2005-2014).

Survival varied widely between diagnostic groups. **Figure 4** presents survival by diagnostic group according to ICCC-3 in children diagnosed between 1995 and 2014. Of 3916 children, 705 (18%) have died. The following numbers describe five-year survival for each main diagnostic group: 99% for Langerhans cell histiocytosis; 96% for germ cell tumours; 95% for renal tumours; 94% for lymphoma; 94% for retinoblastoma; 85% for children with leukaemia; 83% for malignant bone tumours; 78% for neuroblastoma; 76% for hepatic tumours; 75% for soft tissue sarcomas and 74% for central nervous system neoplasms.

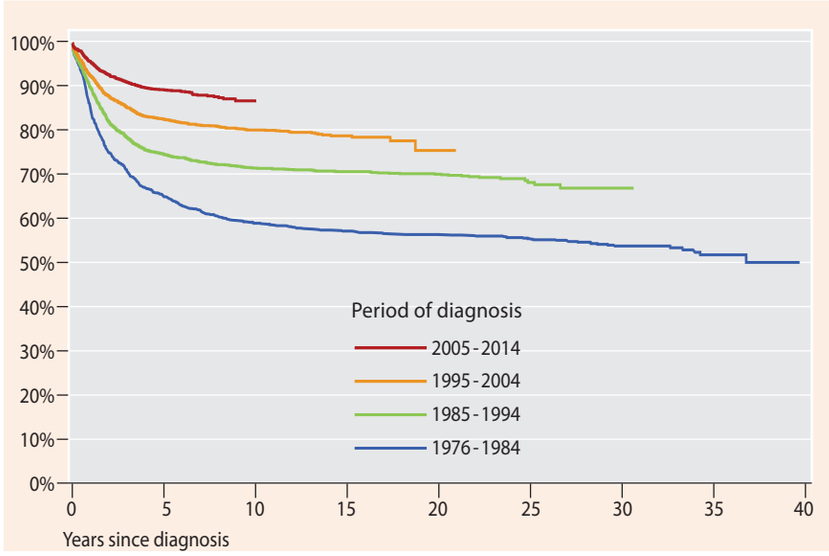


Figure 3
Survival of patients in the SCCR, by period of diagnosis

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1976-2014; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=6604; adjusted for age.

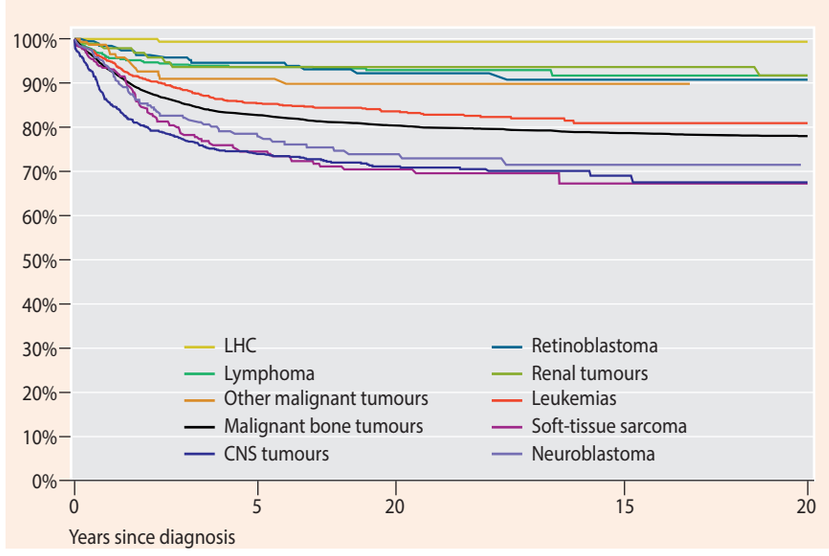


Figure 4
Survival of patients by diagnostic groups according to ICCC-3

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1995-2014 all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=3916; adjusted for age.

Cancer incidence (2005-2014) in Switzerland, for children aged 0-14 years at diagnosis

Table 5 describes the tumours registered in the SCCR during the last ten years (2005-2014). Diagnoses are coded according to ICCC-3, most tumours were more common in boys than in girls.

The age-standardised incidence (according to the European standard population) of any childhood cancer (not including Langerhans cell histiocytosis) was 16.1 per 100,000 person-years. Incidence was highest among children aged 2 years with 24.9 cases per 100,000 person-years (boys 28.0, girls 21.6). Incidence was lowest in 9 year olds with 8.6 cases per 100,000 person-years (boys 9.1, girls 8.0) (**Figure 5** shows crude incidence rates in Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1995-2014; all diagnoses (ICCC-3 but not including Langerhans cell histiocytosis); **Figure 6** shows age- and sex-specific incidence rates for age 0-14).

Table 5
Childhood cancer diagnosed in Switzerland 2005-2014: number of cases, relative frequency, sex ratio, median age at diagnosis and incidence standardised according to the European standard population, by diagnostic groups according to ICCC-3

	Diagnosis	n	Relative frequency	Sex ratio (male:female)	Age at Dx (Median)	Incidence*
I	**Leukaemias, myeloproliferative diseases and myelodysplastic diseases**	**648**	**33,6**	**1,6**	**4,8**	**5,4**
	a. Lymphoid leukaemias	522	80,6	1,5	4,7	4,4
	b. Acute myeloid leukaemias	78	12,0	1,9	4,7	0,7
	c. Chronic myeloproliferative diseases	9	1,4	3,5	10,0	0,1
	d. Myelodysplastic syndrome and other myeloproliferative diseases	32	4,9	3,0	6,3	0,3
	e. Unspecified and other specified leukaemias	7	1,1	0,8	5,5	0,1
II	**Lymphomas and reticuloendothelial neoplasms**	**215**	**11,2**	**1,8**	**10,9**	**1,8**
	a. Hodgkin lymphomas	96	44,7	0,9	12,7	0,8
	b. Non-Hodgkin lymphomas (except Burkitt lymphoma)	58	27,0	2,9	8,9	0,5
	c. Burkitt lymphoma	56	26,0	7,0	7,3	0,5
	d. Miscellaneous lymphoreticular neoplasms	5	2,3	0,3	1,3	0,0
	e. Unspecified lymphomas	0	NA	NA	NA	NA
III	**CNS and miscellaneous intracranial and intraspinal neoplasms**	**442**	**22,9**	**1,2**	**6,8**	**3,7**
	a. Ependymomas and choroid plexus tumour	48	10,9	1,3	2,7	0,4
	b. Astrocytomas	186	42,1	1,1	7,0	1,6
	c. Intracranial and intraspinal embryonal tumours	80	18,1	1,4	6,5	0,7
	d. Other gliomas	52	11,8	1,3	6,5	0,4
	e. Other specified intracranial and intraspinal neoplasms	67	15,2	1,2	10,8	0,6
	f. Unspecified intracranial and intraspinal neoplasms	9	2,0	0,8	8,6	0,1
IV	**Neuroblastoma and other peripheral nervous cell tumours**	**118**	**6,1**	**1,1**	**1,5**	**1,0**
	a. Neuroblastoma and ganglioneuroblastoma	118	100,0	1,1	1,5	1,0
	b. Other peripheral nervous cell tumours	0	NA	NA	NA	NA
V	**Retinoblastoma**	**42**	**2,2**	**0,8**	**1,0**	**0,4**
VI	**Renal tumours**	**98**	**5,1**	**0,8**	**3,3**	**0,8**
	a. Nephroblastoma and other nonepithelial renal tumours	93	94,9	0,8	3,2	0,8
	b. Renal carcinomas	5	5,1	0,7	12,8	0,0
	c. Unspecified malignant renal tumours	0	NA	NA	NA	NA
VII	**Hepatic tumours**	**15**	**0,8**	**2,0**	**2,1**	**0,1**
	a. Hepatoblastoma	14	93,3	1,8	1,9	0,1
	b. Hepatic carcinomas	1	6,7	0,0	14,1	0,0
	c. Unspecified malignant hepatic tumours	0	NA	NA	NA	NA

Table 5 Continued

	Diagnosis	n	Relative frequency	Sex ratio (male:female)	Age at Dx (Median)	Incidence*
VIII	**Malignant bone tumours**	**79**	**4,1**	**0,9**	**11,2**	**0,7**
	a. Osteosarcomas	38	48,1	0,9	11,7	0,3
	b. Chondrosarcomas	1	1,3	0,0	14,4	0,0
	c. Ewing tumour and related sarcomas of bone	39	49,4	1,0	10,9	0,3
	d. Other specified malignant bone tumours	0	NA	NA	NA	NA
	e. Unspecified malignant bone tumours	1	1,3	0,0	14,7	0,0
IX	**Soft tissue and other extraosseous sarcomas**	**139**	**7,2**	**1,4**	**7,8**	**1,2**
	a. Rhabdomyosarcomas	78	56,1	1,4	5,5	0,7
	b. Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	10	7,2	2,3	10,9	0,1
	c. Kaposi sarcoma	0	NA	NA	NA	NA
	d. Other specified soft tissue sarcomas	40	28,8	0,9	11,1	0,3
	e. Unspecified soft tissue sarcomas	11	7,9	4,5	2,8	0,1
X	**Germ cell tumours, trophoblastic tumours, and neoplasms of gonads**	**58**	**3,0**	**1,1**	**6,4**	**0,5**
	a. Intracranial and intraspinal germ cell tumours	15	25,9	2,0	12,1	0,1
	b. Malignant extracranial and extragonadal germ cell tumours	18	31,0	0,6	0,2	0,2
	c. Malignant gonadal germ cell tumours	24	41,4	1,2	11,5	0,2
	d. Gonadal carcinomas	0	NA	NA	NA	NA
	e. Other and unspecified malignant gonadal tumour	1	1,7	0,0	0,8	0,0
XI	**Other malignant epithelial neoplasms and malignant melanomas**	**71**	**3,7**	**0,6**	**12,2**	**0,6**
	a. Adrenocortical carcinomas	2	2,8	1,0	6,4	0,0
	b. Thyroid carcinomas	14	19,7	0,3	13,5	0,1
	c. Nasopharyngeal carcinomas	2	2,8	1,0	13,6	0,0
	d. Malignant melanomas	15	21,1	0,5	10,4	0,1
	e. Skin carcinomas	7	9,9	1,3	7,0	0,1
	f. Other and unspecified carcinoma	31	43,7	0,6	12,0	0,3
XII	**Other and unspecified malignant neoplasms**	**3**	**0,2**	**2,0**	**0,0**	**0,0**
	a. Other specified malignant tumours	2	66,7	1,0	1,8	0,0
	b. Other unspecified malignant tumours	1	33,3	0,0	0,0	0,0
Total (not including Langerhans cell histiocytosis)		**1928**	**100,0**	**1,3**	**6,2**	**16,1**
	Langerhans cell histiocytosis	59	3,0	1,4	5,2	0,5
Total (including Langerhans cell histiocytosis)		**1987**	**100,0**	**1,3**	**6,2**	**16,6**

* Incidence: newly diagnosed tumours in a one year time period per 100,000 persons (person-years)

Swiss residents; age at diagnosis 0-14 years, period of diagnosis 2005-2014, all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=1987

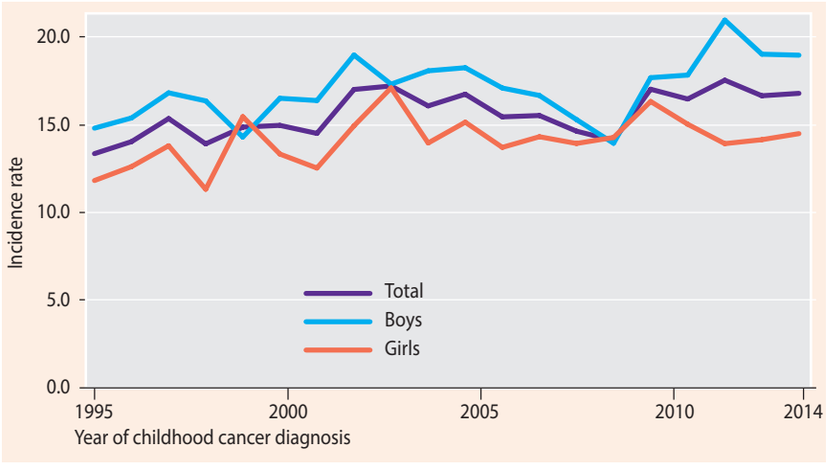


Figure 5
Crude incidence rate (per 100,000 person-years) in Switzerland, by sex and year of diagnosis for the last 20 years (1995-2014)

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1995-2014; all diagnoses (ICCC-3 but not including Langerhans cell histiocytosis); N=3916

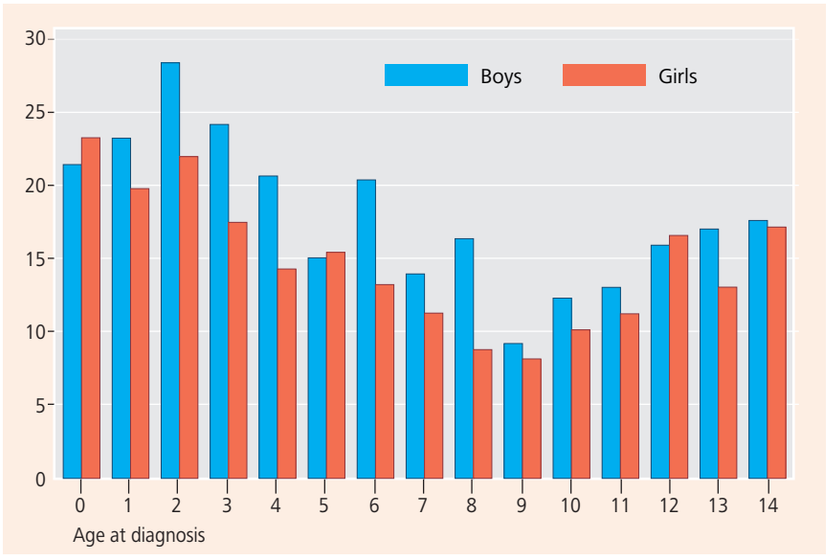


Figure 6
Age- and sex-specific incidence rates (per 100,000 person-years) in Switzerland for the last 10 years

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 2005-2014; all diagnoses (ICCC-3 but not including Langerhans cell histiocytosis); N=1928

3.4 Swiss residents aged 15-20 years at diagnosis (N=501)

Table 6 describes the tumours registered in the last ten years (2005-2014) diagnosed in adolescent patients (aged 15-20 years at diagnosis, N=501). Because data on adolescents are currently not complete within the SCCR, we do not present incidence rates. In adolescents the sex ratio is closer to 1 than in those aged 0-14 years at diagnosis.

Table 6
Adolescent cancer diagnosed in Switzerland 2005-2014: number of cases, relative frequency, sex ratio, median age at diagnosis

	Diagnosis	n	Relative frequency	Sex ratio (male:female)	Age at Dx (Median)
I	**Leukaemias, myeloproliferative diseases and myelodysplastic diseases**	**61**	**12,2**	**1,4**	**16,4**
	a. Lymphoid leukaemias	31	50,8	2,1	15,9
	b. Acute myeloid leukaemias	16	26,2	0,8	16,8
	c. Chronic myeloproliferative diseases	8	13,1	1,0	18,1
	d. Myelodysplastic syndrome and other myeloproliferative diseases	6	9,8	2,0	16,7
	e. Unspecified and other specified leukaemias	0	NA	NA	NA
II	**Lymphomas and reticuloendothelial neoplasms**	**131**	**26,3**	**0,8**	**16,7**
	a. Hodgkin lymphomas	93	71,0	0,8	16,7
	b. Non-Hodgkin lymphomas (except Burkitt lymphoma)	32	24,4	1,0	17,0
	c. Burkitt lymphoma	5	3,8	1,5	17,9
	d. Miscellaneous lymphoreticular neoplasms	1	0,8	0,0	16,6
	e. Unspecified lymphomas	0	NA	NA	NA
III	**CNS and miscellaneous intracranial and intraspinal neoplasms**	**84**	**16,8**	**1,2**	**16,7**
	a. Ependymomas and choroid plexus tumour	6	7,1	1,0	18,3
	b. Astrocytomas	26	31,0	0,7	16,7
	c. Intracranial and intraspinal embryonal tumours	16	19,0	1,7	16,5
	d. Other gliomas	10	11,9	1,0	16,8
	e. Other specified intracranial and intraspinal neoplasms	25	29,8	1,5	16,5
	f. Unspecified intracranial and intraspinal neoplasms	1	1,2	0,0	15,4
IV	**Neuroblastoma and other peripheral nervous cell tumours**	**0**	**NA**	**NA**	**NA**
	a. Neuroblastoma and ganglioneuroblastoma	0	NA	NA	NA
	b. Other peripheral nervous cell tumours	0	NA	NA	NA
V	**Retinoblastoma**	**0**	**NA**	**NA**	**NA**
VI	**Renal tumours**	**7**	**1,4**	**2,5**	**16,6**
	a. Nephroblastoma and other nonepithelial renal tumours	2	28,6	0,0	16,0
	b. Renal carcinomas	5	71,4	1,5	17,4
	c. Unspecified malignant renal tumours	0	NA	NA	NA
VII	**Hepatic tumours**	**2**	**0,4**	**0,0**	**17,4**
	a. Hepatoblastoma	0	NA	NA	NA
	b. Hepatic carcinomas	2	100,0	0,0	17,4
	c. Unspecified malignant hepatic tumours	0	NA	NA	NA
VIII	**Malignant bone tumours**	**48**	**9,6**	**1,5**	**16,2**
	a. Osteosarcomas	33	68,8	1,8	16,3
	b. Chondrosarcomas	1	2,1	0,0	15,1
	c. Ewing tumour and related sarcomas of bone	12	25,0	1,0	16,0
	d. Other specified malignant bone tumours	2	4,2	1,0	16,7
	e. Unspecified malignant bone tumours	0	NA	NA	NA

Table 6 Continued

	Diagnosis	n	Relative frequency	Sex ratio (male:female)	Age at Dx (Median)
IX	**Soft tissue and other extraosseous sarcomas**	**33**	**6,6**	**0,9**	**16,7**
	a. Rhabdomyosarcomas	13	39,4	0,9	16,1
	b. Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	3	9,1	0,0	15,8
	c. Kaposi sarcoma	0	NA	NA	NA
	d. Other specified soft tissue sarcomas	13	39,4	0,4	17,4
	e. Unspecified soft tissue sarcomas	4	12,1	3,0	16,8
X	**Germ cell tumours, trophoblastic tumours, and neoplasms of gonads**	**38**	**7,6**	**8,5**	**17,8**
	a. Intracranial and intraspinal germ cell tumours	3	7,9	0,0	17,2
	b. Malignant extracranial and extragonadal germ cell tumours	0	NA	NA	NA
	c. Malignant gonadal germ cell tumours	33	86,8	15,5	18,0
	d. Gonadal carcinomas	2	5,3	0,0	15,7
	e. Other and unspecified malignant gonadal tumour	0	0,0	NA	NA
XI	**Other malignant epithelial neoplasms and malignant melanomas**	**93**	**18,6**	**0,7**	**18,1**
	a. Adrenocortical carcinomas	1	1,1	0,0	17,0
	b. Thyroid carcinomas	25	26,9	0,1	18,0
	c. Nasopharyngeal carcinomas	3	3,2	2,0	18,7
	d. Malignant melanomas	29	31,2	0,9	18,6
	e. Skin carcinomas	9	9,7	0,8	18,4
	f. Other and unspecified carcinoma	26	28,0	1,4	17,7
XII	**Other and unspecified malignant neoplasms**	**2**	**0,4**	**0,0**	**16,3**
	a. Other specified malignant tumours	2	100,0	0,0	16,3
	b. Other unspecified malignant tumours	0	NA	NA	NA
	Total (not including Langerhans cell histiocytosis)	**499**	**100,0**	**1,1**	**16,8**
	Langerhans cell histiocytosis	2	0,4	1,0	16,4
	Total (including Langerhans cell histiocytosis)	**501**	**100,0**	**1,1**	**16,8**

Age at diagnosis 15-20 years, period of diagnosis 2005-2014, all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=501

4. Research on childhood cancer

The research of the childhood cancer registry focusses on three main topics: Aetiology of childhood cancer, long-term outcomes, and follow-up care after childhood cancer or young adult cancer. These topics are described with their background, aims, methods, recent findings, ongoing studies, and contacts in the remainder of **Chapter 4**. Additional information is available from the investigators and our website (www.childhood-cancerregistry.ch). Further, we thank the supporters for their generous contributions towards the research projects.

All ongoing studies, their funding sources and the senior investigator are summarized in **Table 7**.

Table 7
Research grants of the SCCR, summary

No	Project name	Senior investigator	Funding sources	Study period
Aetiology of childhood cancer				
1	Spatial and spatio-temporal clustering of childhood cancer: The role of infections and environmental hazards	Spycher BD	Swiss Cancer Research (KFS-3515-08-2014)	01.2014-12.2016
2	The spatial epidemiology of childhood cancer in Switzerland	Spycher BD	Swiss National Science Foundation (PZ00P3_147987)	09.2013-08.2016
3	The role of population mixing and exposure to infections in the aetiology of childhood leukaemia: A national cohort study	Spycher BD	Swiss Cancer Research (KFS-3049-08-2012)	01.2013-12.2014
4	Childhood cancer and geographically defined exposures in Switzerland: A census-based nationwide cohort study	Spycher BD	Federal Office of Public Health (12.008357)	03.2013-11.2013
5	Childhood cancer and vicinity of residence to petrol stations and roads: A census-based nationwide cohort study (PETROL)	Kuehni CE	Federal Office of Public Health (10.002946)	06.2010-02.2013
6	Childhood cancer and nuclear power plants in Switzerland: A census-based cohort study	Kuehni CE	Swiss Cancer League (02224-03-2008); Federal Office of Public Health (08.001616)	09.2008-02.2011
Outcome research (Long-term outcomes, follow-up care, international collaboration)				
1	Swiss Childhood Cancer Survivor Study (SCCSS)	Kuehni CE, Angst R Kuehni CE, Bergstraesser E Kuehni CE Von der Weid NX, Kuehni CE Von der Weid NX, Kuehni CE Kuehni CE	Cancer League Aarau Cancer League Zurich Cancer League Bern Swiss Cancer League (KLS-2215-02-2008) Swiss Cancer League (KLS-1605-10-2004) Kinderkrebshilfe Schweiz	01.2012-12.2012 08.2010-07.2011 04.2009-03.2010 07.2008-06.2010 01.2006-10.2008 since 2006
2	PanCare Studies in Fertility and Ototoxicity to improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood (PanCareLIFE)	Kuehni CE Kuehni CE	Swiss Cancer League (KLS-3412-02-2014) EU (FP7-HEALTH-F2-2013-602030; project no. 602030)	07.2014-06.2017 11.2013-10.2018
3	Dietary habits, nutrition and risk of late effects after childhood cancer	Bochud M, Kuehni CE	Swiss Cancer League (KLS-3644-02-2015)	07.2015-06.2018
4	Psychological late effects in long-term childhood cancer survivors – Development of guidelines for follow-up care	Michel G	Krebsliga Zentralschweiz	11.2015-10.2017
5	PanCare childhood and adolescent cancer survivor care and follow-up studies (PanCareSurFup)	Kuehni CE Kuehni CE	Swiss Cancer Research (KFS-02783-02-2011) EU (FP7-HEALTH-F2-2010-257505; project no. 257505)	08.2011-07.2014 02.2011-01.2017
6	Mortality after cancer in childhood and adolescence	Kuehni CE Kuehni CE	Swiss National Science Foundation (PDFMP3_141775) Swiss Bridge	08.2012-08.2015
7	Follow-up care after childhood and young adult cancer (CCFU)	Michel G	Swiss National Science Foundation (PZ00P3_121682 and PZ00P3_141722)	08.2009-08.2014
8	Effectiveness of transition from paediatric to adult care after childhood cancer	Michel G	Swiss Cancer League (KFS-02631-08-2010)	04.2011-04.2014

No	Project name (continued)	Senior investigator	Funding sources	Study period
9	Parents of long-term childhood cancer survivors	Michel G	Swiss National Science Foundation (100019_153268/1) Kinderkrebshilfe Schweiz	since 2013
10	Fertility after Chemo- and Radiotherapy in Childhood and Adolescence, FeCt – Multicentre	Michel G	Kinderkrebshilfe Schweiz	since 2012
11	Risk of cancer and long-term mortality in children treated with growth hormone:	Mullis P, Kuehni CE	Swiss Cancer League (KLS-2948-02-2012)	07.2012-12.2013
	Swiss participation in the EU FP7 project (SAGhE)	Mullis P	EU (FP-HEALTH-F2-2009-223497)	04.2011-03.2014
		Mullis P, Kuehni CE	Swiss Cancer League (KLS-02586-02-2010)	07.2010-12.2012

4.1 Aetiology of childhood cancer

Background

The aetiology of childhood cancers remains largely unknown. For leukaemia, the most frequent childhood cancer, known risk factors include trisomy 21, certain rare genetic syndromes, some common germline genetic variants, high birthweight, and high parental age at birth. Regarding environmental exposures, only ionising radiation at medium to high doses is an established risk factor – both for leukaemia and CNS tumours. Numerous other environmental factors are being discussed as potential risk factors. These include: low dose ionising radiation (e.g. natural background radiation and diagnostic radiation), traffic related air pollution, electromagnetic fields (e.g. from power lines, radio and TV transmitters, or mobile phones) pesticides, and infections.

Aims

The broad aims of the research group are to investigate whether:

- Cancer risks in children are associated with environmental exposures, such as ionising and non-ionising radiation, air pollution and exposure to infectious diseases, as well as parents workplace exposures;
- Cancer risks in children are associated with socioeconomic, family or perinatal exposures;
- Cases of cancer tend to cluster in space and/or in space and time and, if yes, to elicit aetiological clues from the pattern of clustering.

Methods

Clinical and residential information on diagnosed cases are obtained from the SCCR. Data on the population at risk are obtained from the Swiss National Cohort (SNC) which includes the entire Swiss resident population at census time points (1990, 2000, and annually from 2010 onward). Record linkage between the two datasets allows investigating cancer incidence on a nationwide scale with a cohort design. The SCCR collects geocoded address histories from birth to diagnosis allowing to distinguish different exposure time windows. Geocoded places of residence are also available for the entire population from the SNC. This allows calculating geographically determined exposures such as distance to highways or NO_2 concentration levels (based on spatial pollution models) for the entire population at risk. The SNC also provides demographic, socioeconomic and perinatal data for the entire population. The availability of precise geocodes of residence allows assessing spatial and spatio-temporal clustering using methods for point pattern data rather than methods for less precise regional count data (e.g. aggregated at municipality level).

Current status

A, Recent findings: A summary of our recent research and findings is given in [Lupatsch-2016a]. We found evidence of increased risks of childhood leukaemia and CNS tumours among children exposed to higher levels of natural background radiation (terrestrial gamma and cosmic radiation) [Spycher-2015a, 2015b, 2015c]. Young children living in the immediate proximity (<100m) of highways were found to have an increased leukaemia risk [Spycher-2015d]. We found little evidence of associations between childhood leukaemia and commonly used measures of population mixing [Lupatsch-2015b, c] or for associations between leukaemia risk and socioeconomic status [Adam-2015]. However, we did find evidence of a temporal association between childhood leukaemia and periods of rapid population growth in Swiss municipalities [Lupatsch-2016d]. We found evidence for spatio-temporal clustering of leukaemia around the time of birth, but not around the time of diagnosis [Kreis-2016].

B, Ongoing studies: In ongoing studies we are investigating whether: i) Childhood cancer is associated with increased air concentrations of benzene and NO_2; ii) Childhood leukaemia is associated with perinatal characteristics (including parental age, birth order, age difference to next older sibling, and birth weight); iii) Cases of childhood leukaemia born close in time and space to another case (clustered cases) differ from non-clustered cases with respect to diagnostic, socioeconomic characteristics and environmental exposures; and iv) whether there is evidence for spatial clustering in Switzerland. Furthermore, we are v) collaborating in an international case control study on the association between childhood cancer and proximity to power lines.

Contact

The research team consists of Ben Spycher, Claudia Kuehni, Christian Kreis and Garyfallos Konstantinoudis.

4.2 Long-term outcomes

Background

Cancer is the most common disease-related cause of death during childhood in the Western world. Thanks to therapeutic improvements in the recent decades, survival rates for childhood cancer now exceed 80%, leading to a growing population of long-term survivors. However, cancer and its treatment can cause adverse late effects, such as second primary malignancies, cardiovascular disease, hearing loss and infertility. These adverse late effects may affect survivors' health, health behaviour and quality of life, and may lead to premature death. Comprehensive data on the burden of late effects of childhood cancer including premature mortality and their risk factors are scarce. The SCCR has a broad research program focusing on long-term outcomes that includes the national Swiss Childhood Cancer Survivor Study (SCCSS) and a study on cause-specific long-term mortality.

Aims

The research group aims:

- To investigate prevalence, incidence and spectrum of somatic and psychosocial outcomes including second primary neoplasms, somatic health, mental health, educational and social outcomes, health-related quality of life, and cause-specific long-term mortality.
- To determine sociodemographic, cancer- and treatment related predictors associated with long-term outcomes.
- To describe health behaviours in long-term survivors.

Methods

This prospective cohort study is based on children and adolescents registered in the SCCR.

Study population: All individuals who are at least 5-year survivors, who were diagnosed with cancer at age < 21 years, and were Swiss residents at time of diagnosis are eligible.

Collected data: A detailed questionnaire is sent to childhood cancer survivors and their parents to obtain data about somatic, psychosocial, and mental health outcomes. For comparison, a similar questionnaire is sent to siblings of survivors. Questionnaire data are complemented with phone interviews to patients and are validated with information from general practitioners and hospital records, e.g. audiometric or lung function tests to validate hearing problems or lung diseases. Furthermore, we collect data from municipal population registries to obtain vital statistics including dates of death, and Swiss mortality statistics to obtain causes of death. For some studies, we also collect saliva samples for genetic analyses. These broad data make it possible to investigate prevalence and incidence of adverse late effects and to identify their predictors in Swiss survivors.

Response rate: For the SCCSS questionnaire survey, we contacted 2930 five-years survivors aged 0 to 16 years at diagnosis, 2235 (76%) completed our questionnaire. Among 598 contacted survivors aged 16-20 years at diagnosis whom we contacted, 320 (57%) participated. We also contacted 1522 siblings, of whom 866 (57%) participated.

Current status

A, Recent findings

This study offers the first national-level data on adverse late effects, health behaviour, survival and long-term mortality after cancer in childhood and adolescence in Switzerland. The study is ongoing and we are currently contacting new 5-year survivors diagnosed between 2005-2010. We obtained causes of death of 3965 of the 5-year survivors who subsequently died. We analyse and publish our findings continuously. Previous publications have included topics like health-related quality of life, education, cognitive problems, partnership, income, physical activity, nutrition, survival, and mortality. Our findings will help to identify patients who are at increased risk for late effects, to adjust therapies and to develop tailored follow-up programs for survivors.

Health-related quality of life (HRQoL): We found that the overall HRQoL of young survivors (8-16 years) was comparable to population norms for most parent-reported dimensions and higher for most self-reported dimensions [Wengenroth-2015]. However, older survivors (>16 years) had lower HRQoL than their siblings, and among survivors, those with chronic health problems had the lowest health-related quality of life [Rueegg-2013]. Survivors of acute lymphoblastic leukemia reported good HRQoL, even after a relapse [Essig-2012].

Educational and social outcomes: We also showed that survivors achieved educational levels similar to the general population [Kuehni-2012]. Survivors younger than 20 years were more likely than their siblings to report cognitive problems [Wengenroth-2015]. We found lower personal income in survivors than in siblings [Wengenroth-2016]. However, survivors' personal income may increase later because treatment can push back education and carreer training and cause survivors to start working later than their peers. Survivors are less likely than peers to be married or in a life partnership [Wengenroth-2014]. This might be because survivors take longer to reach their final educational achievement, which might in turn encourage them to delay marriage.

Physical activity: We found that daily physical activity and sport levels in survivors were similar to the general population. Physical activity was mainly determined by socio-demographic and cultural factors [Rueegg-2012a]. However, we found that survivors are at high risk of suffering from performance limitations in sports and in daily living activities and that these limitations differed strongly between diagnostic groups [Rueegg-2012b]. Despite these physical performance limitations, many survivors maintained healthy activity levels [Rueegg-2013].

Nutrition: We showed that the adherence to dietary recommendations among survivors was similar to their siblings and the general population, but poor overall [Belle-submitted].

Hearing loss: We found that the burden of hearing loss as a late effect after ototoxic cancer treatment has stabilized in recently treated survivors, which suggests that survivors have benefited from new treatment regimens that use less ototoxic

radiation and more carefully dosed platinum compounds [Weiss - accepted].

Mortality: We found that the mortality of five-year survivors of childhood cancers is elevated compared to the general population, with recurrence and progression of the original cancer as the most common causes of death up to 24 years after diagnosis [Schindler-2016].

B, Ongoing studies

Ongoing studies focus on different somatic health problems and health behaviours:

i) diseases; ii) cardiac diseases; iii) hearing loss; and iv) dietary habits and excess weight. We are also collaborating with international studies (see International collaborations).

Contact

The research team consists of Claudia Kuehni, Fabiën Belle, Rahel Kasteler, Rahel Kuonen, Matthias Schindler, Grit Sommer, Annette Weiss, Gisela Michel and Nicolas von der Weid.

4.3 International collaborations

Background

Late effects of childhood cancer and its treatment are common, but numbers in individual countries are low. Therefore, pooling of data into large international cohorts is essential to identify risk factors for late effects using observational data and genetic tools. Survivors can benefit from personalized, evidence-based care based on their individual risk; and future patients may benefit from adapted treatment, that cause less severe side effects.

International studies on childhood cancer often also include systematic reviews that summarize the evidence on risk factors of late effects. These provide the basis for creating new guidelines for the clinical long-term follow-up of survivors of cancer diagnosed at a young age.

The SCCR collaborates with other childhood cancer cohorts [Bhatia-2015, Winther-2015], participates in European studies to investigate late effects, and is involved in the development of international guidelines for clinical long-term follow-up of childhood and adolescent cancer survivors.

Aims

Within the international collaborations, we aim to investigate:

- Prevalence and incidence of late effects of childhood and adolescent cancer and its treatment
- Risk factors for these late effects

We also aim to develop guidelines to improve the health and quality of life of current and future survivors of childhood cancer.

Methods

Swiss patients of childhood and adolescence cancer are part of a Pan-European cohort. Researchers within this European collaboration can then select patients with late effects, for example patients with a second primary cancer, cardiac or hearing problems, for nested case-control or case-cohort studies. Within these studies, researchers can identify non-genetic and genetic risk factors of late effects.

Experts and the International Guideline Harmonization Group (IGHG, http://www.ighg.org/) write up systematic reviews to develop evidence-based, standardised guidelines for clinical follow-up of survivors.

Current status

A, Ongoing studies:

Swiss patients of childhood and adolescence cancer are part of Pan-European cohorts. Researchers within this European collaboration can then select patients with late effects, for example patients with a second primary cancer, cardiac or hearing problems, for nested case-control or case-cohort studies. Within these studies, researchers can identify non-genetic and genetic risk factors of late effects. Currently, we are collaborating in two ongoing studies:

PanCareSurFup (PanCare childhood and adolescent cancer survivor care and follow-up studies; http://www.pancaresurfup.eu/)

This project investigates the burden and risk factors of the most severe and life threatening late effects, namely second primary neoplasms, cardiovascular disease and premature death. We contributed with 4719 Swiss 5-year survivors to the Pan-European cohort and with detailed treatment data from medical records of 139 Swiss survivors to the European nested-case control studies.

Recent findings: A new method to facilitate valid and consistent grading of cardiac events in childhood cancer survivors has been published [Feijen-2014] and several other publications are in preparation.

PanCareLIFE (PanCare Studies in Fertility and Ototoxicity to Improve Quality of Life after Cancer during Childhood, Adolescence and Young Adulthood; http://www.pancarelife.eu/)

This project investigates hearing loss, infertility and quality of life. We identified survivors at risk for hearing loss and collected their audiograms. We will contribute questionnaire data on hearing loss, fertility and quality of life from the SCCSS. We will be responsible, together with the University of Münster in Germany, for the statistical analysis of quality of life data from eight European countries.

B, Development of guidelines

In close collaboration with European and American experts and the International Guideline Harmonization Group (IGHG, http://www.ighg.org/), we write systematic reviews do develop evidence-based, standardized guidelines for clinical follow-up of survivors. We are currently involved as chairs, work group (WG) leaders and group members in the development of the following guidelines:

- *Hearing loss (ototoxicity)*
  - Chairs: Wendy Landier (USA), Richard Cohn (AUS)
  - WG leaders: Claudia Kuehni (CH), Thorsten Langer (DE)
- *Pulmonary dysfunction*
  - Chairs and WG leaders: Claudia Kuehni (CH), Andrew Dietz (USA)
- *Fatigue, mental health and psychosocial problems*
  - Chairs: Gisela Michel (CH), Jordan Gilleland Marchak (USA)
  - Fatigue WG leaders: Kathrin Scheinemann (CH), Gisela Michel (CH)
  - Mental Health WG leaders: Janine Vetsch (CH), Jordan Gilleland Marchak (USA)

Once the guidelines will be available, all centres of the Swiss Paediatric Oncology Group will implement these guidelines in Switzerland.

Recent findings: A survey among paediatric oncology/haematology clinics from 44 European countries found that many clinics have insufficient or lack programmes for long-term follow-up into adulthood for survivors of childhood cancer [Brown-2015]. This study showed that available guidelines are not universally used throughout Europe and we need to further develop and disseminate Pan-European long-term follow-up guidelines.

Contact

The research team consists of Claudia Kuehni, Rahel Kasteler, Rahel Kuonen, Grit Sommer, Annette Weiss, Gisela Michel and Nicolas von der Weid.

4.4 Psychosocial outcomes and follow-up care

Background

Treatment for cancer in children and young adults has greatly improved and most patients can be cured today. However, more than 50% of survivors of childhood cancer suffer from late effects. Similarly, parents might suffer long after their child has been cured. To detect and treat late effects as early as possible, most survivors should continue to attend follow-up care long after their cancer has been cured. Follow-up care needs to be constantly updated to meet the current status of research. International guidelines summarising the care needed after different cancers and treatment are necessary. Additionally, while various models of follow-up care have been described, so far none has been implemented in Switzerland. A successful model must not only take clinical aspect into account but also survivors' preferences and needs.

Aims

The research group aims to:

- Describe follow-up care models available across Europe, and preferences for a follow-up model among Swiss childhood and young adult cancer survivors, parents and physicians (oncologists and general practitioners)
- Evaluate the transition/transfer from paediatric to adult care in survivors of childhood cancer
- Describe psychological and socio-demographic outcomes, as well as needs in parents of long-term childhood cancer survivors

Methods

To describe follow-up care models in Europe, we invited 198 clinics and follow-up programmes in Europe to complete a questionnaire survey describing the follow-up care available at their institution. To assess preferences for different models of follow-up care, a questionnaire survey assessed opinions and perspectives on both currently used and desired optimal follow-up care among survivors, parents, paediatric and adult oncologists / haematologists and family practitioners. We evaluated the transition from paediatric to adults among childhood cancer survivors using medical records. Finally, we will contact parents in a questionnaire survey to assess positive and negative psychological, familial, and social outcomes [Mader-2016]. These outcomes will be compared to the Swiss general population.

Current status

A, Recent Findings:

Follow-up care: Our survey among European paediatric oncology/haematology clinics found that many still lacked programmes for long-term follow-up into adulthood [Essig-2012, Brown-2015]. Additionally, a large proportion of Swiss survivors do not attend regular follow-up care [Michel-2011, Rebholz-2011, Lupatsch-2016e]. Survivors and their parents desire precise information on late effects and follow-up care [Gianinazzi-2014a, Vetsch-2015]. Most survivors and parents reported preferences for care by a specialist (oncologist) [Vetsch-2016, Christen-2016].

Psychological late effects: We found that survivors are at increased risk for psychological distress [Michel-2010, Gianinazzi-2013, Gianinazzi-2014b, Michel-2015, Gianinazzi-2016] or other negative psychosocial outcomes [Wengenroth-2014, 2015a, 2015b, Kuehni-2012a, Rebholz-2012].

Transition: In Switzerland, there is no specialised transition programme for survivors of childhood cancer from paediatric to adult care. We investigated if patients are receiving e.g. follow-up information after release from the paediatric oncology clinic [Gianinazzi-2015]. Patient-adapted information on diagnosis, treatment and future follow-up, provided at the time of discharge, was rarely found.

B, Ongoing studies:

The study on parents of childhood cancer survivors will be the first population-based study among parents of long-term survivors of childhood cancer and will shed light on their psychological well-being, social outcomes and the needs they have for their children and themselves.

Contact

The research team consists of Gisela Michel, Katharina Roser, Luzius Mader, Julia Bänziger, Janine Vetsch, Salome Christen, Claudia Kuehni, and Nicolas von der Weid.

5. Publications of the Swiss Childhood Cancer Registry

All articles published using SCCR data from January 2007 – June 2016 are reported below. Additional publications related to the SCCR or SPOG can be found on the SCCR and SPOG websites: www.childhoodcancerregistry.ch and www.spog.ch.

5.1 Original articles (Peer reviewed journals)

2016

1. Adam M, Rueegg CS, Schmidlin K, Spoerri A, Niggli F, Grotzer M, von der Weid NX, Egger M, Probst-Hensch N, Zwahlen M, Kuehni CE. Socioeconomic disparities in childhood cancer survival in Switzerland. Int J Cancer. 2016; 138(12):2856-66.
2. Christen S, Vetsch J, Mader L, Dehler S, Korol D, Kuehni CE, Rueegg CS, Michel G. Preferences for the organization of long-term follow-up in adolescent and young adult cancer survivors. Support Care Cancer. 2016; 24(8):3425-36.
3. Essig S, Steiner C, Kuehni CE, Weber H, Kiss A. Improving Communication in Adolescent Cancer Care: A Multiperspective Study. Pediatr Blood Cancer. 2016; 63(8):1423-30.
4. Gianinazzi ME, Rueegg CS, Vetsch J, Luer S, Kuehni CE, Michel G, Swiss Pediatric Oncology G. Cancer's positive flip side: posttraumatic growth after childhood cancer. Support Care Cancer. 2016; 24(1):195-203.
5. Kreis C, Grotzer M, Hengartner H, Daniel Spycher B, Swiss Paediatric Oncology G, the Swiss National Cohort Study G. Space-time clustering of childhood cancers in Switzerland: A nationwide study. Int J Cancer. 2016; 138(9):2127-35.
6. Lupatsch JE, Kreis C, Zwahlen M, Niggli F, Ammann RA, Kuehni CE, Spycher BD, Swiss Paediatric Oncology G, Swiss National Cohort Study G. Temporal association between childhood leukaemia and population growth in Swiss municipalities. Eur J Epidemiol. 2016d.
7. Lupatsch JE, Wengenroth L, Rueegg CS, Teuffel O, Gumy-Pause F, Kuehni CE, Michel G, Swiss Paediatric Oncology G. Follow-Up Care of Adolescent Survivors of Childhood Cancer: The Role of Health Beliefs. Pediatr Blood Cancer. 2016e; 63(2):318-25.
8. Mader L, Rueegg CS, Vetsch J, Rischewski J, Ansari M, Kuehni CE, Michel G, Swiss Paediatric Oncology G. Employment Situation of Parents of Long-Term Childhood Cancer Survivors. Plos ONE. 2016; 11(3):e0151966.
9. Mulder RL, van der Pal HJ, Levitt GA, Skinner R, Kremer LC, Brown MC, Bardi E, Windsor R, Michel G, Frey E. Transition guidelines: An important step in the future care for childhood cancer survivors. A comprehensive definition as groundwork. Eur J Cancer. 2016; 54:64-8.
10. Schindler M, Spycher BD, Ammann RA, Ansari M, Michel G, Kuehni CE, Swiss Paediatric Oncology G, Swiss Paediatric Oncology Group S. Cause-Specific Long-Term Mortality in Survivors of Childhood Cancer in Switzerland: A Population Based Study. Int J Cancer. 2016; 139(2):322-33.
11. Vetsch J, Rueegg CS, Mader L, Bergstraesser E, Rischewski J, Kuehni CE, Michel G, Swiss Paediatric Oncology G. Follow-up care of young childhood cancer survivors: attendance and parental involvement. Support Care Cancer. 2016; 24(7):3127-38.
12. Vienneau D, Infanger D, Feychting M, Schuz J, Schmidt LS, Poulsen AH, Tettamanti G, Klaeboe L, Kuehni CE, Tynes T, Von der Weid N, Lannering B, Roosli M. A multinational case-control study on childhood brain tumours, anthropogenic factors, birth characteristics and prenatal exposures: A validation of interview data. Cancer Epidemiol. 2016; 40:52-59.
13. Wengenroth L, Sommer G, Schindler M, Spycher BD, von der Weid NX, Stutz-Grunder E, Michel G, Kuehni CE, Swiss Paediatric Oncology G. Income in Adult Survivors of Childhood Cancer. Plos ONE. 2016; 11(5):e0155546.

2015

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2015

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Schweizer Krebsbulletin

2016

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2012

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2008

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5.5 Reports

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2015

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6. Appendix: Classification of cancer diagnoses

International Classification of Childhood Cancer - ICCC-3

The third edition of the International Classification of Childhood Cancer (ICCC-3) represents the standard for presentation of international data on childhood cancer incidence and survival. It applies the rules, nomenclature and codes (morphology, topography and behaviour) of the ICD-O-3. ICCC-3 categories are defined in conformity with international classifications of the pathology and genetics of childhood cancers. In the ICCC-3, three hierarchical levels have been developed: level one consists of 12 main diagnostic groups and level two of 47 diagnostic subgroups. These two levels of the ICCC-3 allow standardised comparison of the broad categories of childhood tumours. Level three, an optional «extended» classification, comprises two to eleven divisions of selected diagnostic subgroups. The division of some diagnostic subgroups, e.g. leukaemia and Non-Hodgkin lymphomas, reflects the availability of detailed cytogenetic or molecular information that permits homogeneous groups of tumours to be distinguished within them and thus allows their separate study. The Swiss childhood cancer registry (SCCR) uses level one to three. Only malignant neoplasms are classified in ICCC-3, with the exception of non-malignant intracranial and intraspinal tumours. Tumours known to occur only rarely in young patients are also included in ICCC-3. The ICCC-3 is used if data are compared with other childhood cancer registries.

International Statistical Classification of Diseases for Oncology - ICD-O-3

The third edition of the International Statistical Classification of Diseases for Oncology (ICD-O-3) has been developed by a working group hosted by the International Association of Research in Cancer (IARC) and WHO. The morphology code for neoplasm has been revised, especially for lymphomas and leukaemia. In contrast to the International Classification of Diseases, 10th revision (ICD-10), ICD-O-3 uses only one set of four characters for topography (based on the malignant neoplasm section of ICD-10). The topography code remains the same for all neoplasms of that site. The behaviour code is incorporated as the fifth digit in the morphology field. It identifies whether the tumour is malignant, benign, of uncertain or unknown behaviour, in situ, presumed to be primary or secondary. For all tumours diagnosed since 1st January 2014 the SCCR uses the 2011 updates to ICD-O-3 which include new terms, codes and behaviour combinations. This allows e.g. B lymphoblastic leukaemias to be further classified according to their exact cytogenetic and molecular characteristics, which are relevant for disease prognosis. ICD-O-3 is used to compare data with general cancer registries.

International Statistical Classification of Diseases and Related Health Problems - ICD-10

The International Statistical Classification of Diseases and Related Health Problems (ICD) permits the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different regions and at different time periods. The ICD has become the international standard diagnostic classification for all general epidemiological purposes. The ICD-10 classification comprises three volumes: Volume 1 contains the main classifications; Volume 2 provides guidance for users of the ICD; and Volume 3 is the alphabetical index to the classification. Classification is divided into 21 chapters. The first character of the ICD code is a letter. Each letter is associated with a particular chapter, e.g. the letter D is used in both chapter II «Neoplasms» and chapter III «Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism». The topography code in Volume 3 describes the site and the behaviour of the neoplasm: malignant, secondary or metastatic, in situ, benign or of unknown behaviour. The morphology codes listed in Volume 1 are the same as those used in the special adaptation of the ICD for oncology, the ICD-O97.

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