swiss childhood cancer registry

annual report 2015 - 2016

Swiss Childhood Cancer Registry
Annual Report 2015/2016

For the Swiss Childhood Cancer Registry

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Bern, Swiss Childhood Cancer Registry

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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. 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 2016, data from of 10391 cases (diagnosed in 10250 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 more than 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 eighth report covers the routine analyses of all children diagnosed between 1st January 1976 and 31st December 2016. Activities, research and publications of the SCCR are described for the years 2016 to 2017. 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 2016 **(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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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 the 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 2015/2016

- 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 2015/2016

- National Institute for Cancer Epidemiology and Registration (NICER)
- Federal Office of Health (FOH)
- Kinderkrebs Schweiz
- Celgene GmbH
  (through Förderverein Schweizer Kinderkrebsregister)
- Amgen Switzerland AG
  (through Förderverein Schweizer Kinderkrebsregister)
- CSL Behring
  (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 2016. 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=10391)

This chapter describes data from all cases diagnosed 1976-2016, resident in Switzerland or abroad, diagnosed or treated in Switzerland (N=10391).

Up to 31st December 2016, a total of 10391 cases classifiable according to the ICCC-3, or Langerhans cell histiocytosis (LCH), have been registered in the SCCR. These tumours were diagnosed in 10250 patients. Among these, 10250 patients had only one primary neoplasm, 137 patients had two primary neoplasms and 4 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 (2012-2016), a total of 1539 newly diagnosed cases were registered; among them 1335 cases in Swiss residents **(Table 1)**.

Swiss residents account for 9255 (89%) of all cases and foreign residents for 1136 (11%) cases **(Table 2)**. Swiss residents make up 35% (179/513) of all retinoblastoma patients, while foreign residents make up 65% (334/513) 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.

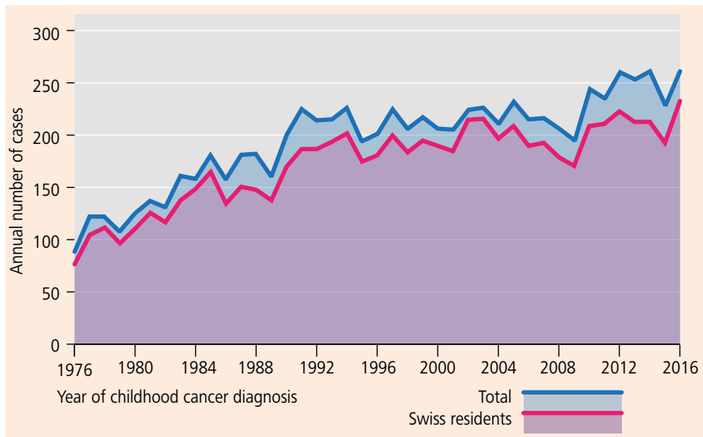


Figure 1
Annual number of registered cases over time
Swiss and foreign residents, age at diagnosis 0-14 years; period of diagnosis 1976-2016; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=8019

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

Year of diagnosis	All patients		Swiss residents		Foreign residents	
	Age at diagnosis (years)		Age at diagnosis (years)		Age at diagnosis (years)	
	0-14	15-20	0-14	15-20	0-14	15-20
1976-1981	702	185	622	167	80	18
1982-1986	789	252	699	233	90	19
1987-1991	949	292	789	271	160	21
1992-1996	1050	329	934	296	116	33
1997-2001	1059	340	949	321	110	19
2002-2006	1108	393	1022	366	86	27
2007-2011	1096	308	958	293	138	15
2012-2016	1266	273	1070	265	196	8
	8019	**2372**	**7043**	**2212**	**976**	**160**

Swiss and foreign residents, age at diagnosis 0-20 years; period of diagnosis 1976-2016; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=10391

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)	
Switzerland	9255	89,1	7043	87,8	2212	93,3
Foreign countries	1136	10,9	976	12,2	160	6,7
Europe	803	7,7	710	8,9	93	3,9
Neighbouring countries	431	4,1	369	4,6	62	2,6
Austria	11	0,1	11	0,1	0	0,0
France	152	1,5	115	1,4	37	1,6
Germany	84	0,8	79	1,0	5	0,2
Italy	183	1,8	163	2,0	20	0,8
Liechtenstein	1	0,0	1	0,0	0	0,0
Other European countries	372	3,6	341	4,3	31	1,3
Middle East	40	0,4	33	0,4	7	0,3
North Africa	162	1,6	125	1,6	37	1,6
Other African countries	52	0,5	44	0,5	8	0,3
Other countries	65	0,6	56	0,7	9	0,4
Abroad	13	0,1	8	0,1	5	0,2
Total	**10391**	**100,0**	**8019**	**100,0**	**2372**	**100,0**

Swiss and foreign residents, age at diagnosis 0-20 years; period of diagnosis 1976-2016; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=10391

3.3 Swiss residents aged 0-14 years at diagnosis (N=7043)

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%).

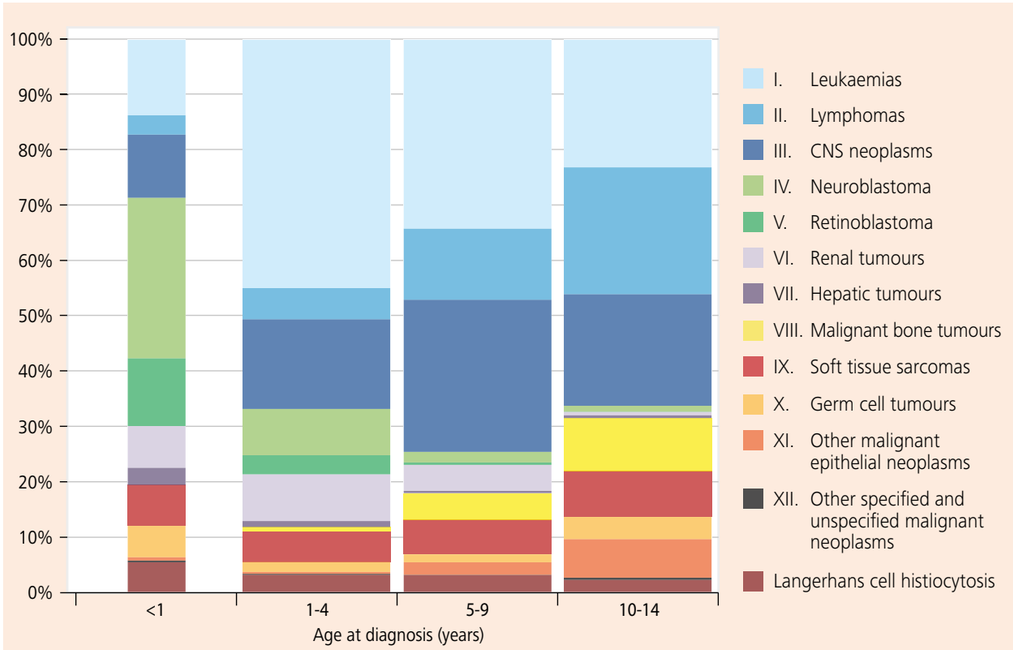
Germ cell tumours may arise in the gonads (ovaries and testes), or in other sites, such as the brain (intracranial germ cell tumours). Soft tissue sarcomas (7%), and malignant bone tumours (4%) arise from abnormal connective tissue. Occasionally, children also develop carcinomas such as melanomas or 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

Diagnosis	All children		By age at diagnosis (years)							
			<1		1-4		5-9		10-14	
	n	%	n	%	n	%	n	%	n	%
I Leukaemias, myeloproliferative diseases and myelodysplastic diseases	2297	32,6	99	14,4	1095	44,7	635	33,7	468	23,2
II Lymphomas and reticuloendothelial neoplasms	871	12,4	23	3,3	133	5,4	249	13,2	466	23,1
III Central nervous system neoplasms	1409	20,0	80	11,6	405	16,5	515	27,3	409	20,3
IV Neuroblastoma and other peripheral nervous cell tumours	472	6,7	197	28,6	215	8,8	40	2,1	20	1,0
V Retinoblastoma	178	2,5	86	12,5	83	3,4	8	0,4	1	0,0
VI Renal tumours	358	5,1	51	7,4	207	8,5	88	4,7	12	0,6
VII Hepatic tumours	67	1,0	22	3,2	25	1,0	9	0,5	11	0,5
VIII Malignant bone tumours	305	4,3	0	0,0	19	0,8	92	4,9	194	9,6
IX Soft tissue and other extraosseous sarcomas	471	6,7	51	7,4	135	5,5	120	6,4	165	8,2
X Germ cell tumours, trophoblastic tumours and neoplasms of gonads	188	2,7	39	5,7	43	1,8	27	1,4	79	3,9
XI Other malignant epithelial neoplasms and malignant melanomas	203	2,9	5	0,7	10	0,4	44	2,3	144	7,1
XII Other specified and unspecified malignant neoplasms	14	0,2	2	0,3	4	0,2	1	0,1	7	0,3
Langerhans cell histiocytosis	210	3,0	34	4,9	74	3,0	59	3,1	43	2,1
Total	**7043**	**100,0**	**689**	**100,0**	**2448**	**100,0**	**1887**	**100,0**	**2019**	**100,0**

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1976-2016; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=7043

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



Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1976-2016; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N = 7043

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 6980 patients, 1701 (24%) have died, and 5279 (76%) are still alive (**Table 4**). Among these, most (4813) have been followed-up during the past 8 years, 305 (6%) have last been followed up between 2004 and 2008, and only 161 (3%) before 2004. Among the latter, 111 (38 between 2004-2008 and 73 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	**5279**	**75,6**
Last clinical follow-up after 2008	4813	91,2
Last clinical follow-up 2004-2008	305	5,8
Last clinical follow-up before 2004	161	3,0
Deceased	**1701**	**24,4**
Total	**6980**	**100,0**

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1976-2016; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=6980 patients (7043 cases)

Survival

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

Ten-year survival increased from 53% in children diagnosed between 1976 and 1986, to 66% in children diagnosed between 1987-1996, 79% in children diagnosed between 1997 and 2006, and 87% in children diagnosed within the last decade (2007-2016).

Survival varied widely between diagnostic groups. **Figure 4** presents survival by diagnostic group according to ICCC-3 in children diagnosed between 1997 and 2016. Of 3954 children, 658 (17%) 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 lymphoma; 94% for retinoblastoma; 93% for renal tumours; 86% for children with leukaemia; 79% for neuroblastoma; 79% for hepatic tumours; 76% for soft tissue sarcomas; 74% for central nervous system neoplasms and 73% for malignant bone tumours.

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

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1976-2016; all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=7043; adjusted for age.

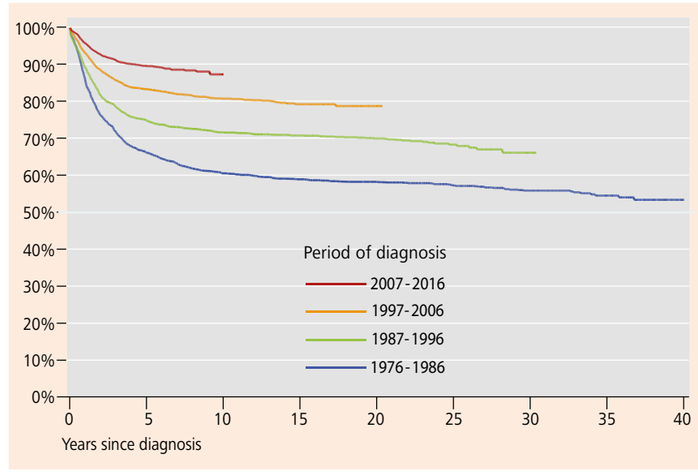
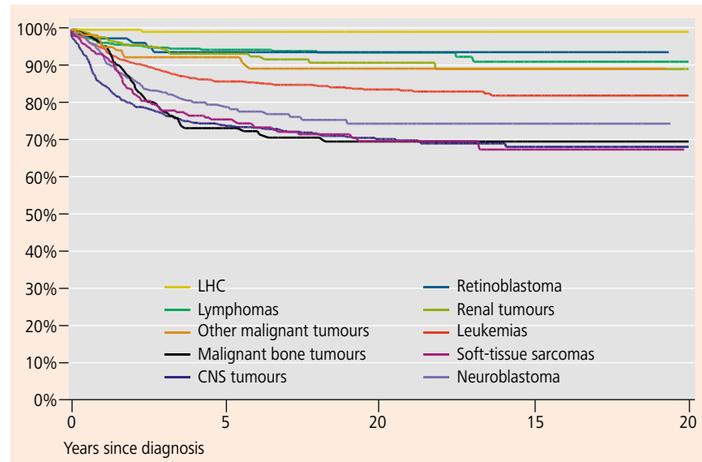


Figure 4
Survival of patients by diagnostic groups according to ICCC-3

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1997-2016 all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=3954; adjusted for age.



Cancer incidence (2007-2016) in Switzerland, for children aged 0-14 years at diagnosis

Table 5 describes the tumours registered in the SCCR during the last ten years (2007-2016). Diagnoses are coded according to ICCC-3.

The age-standardised incidence (according to the European standard population) of any childhood cancer (not including Langerhans cell histiocytosis) was 16,3 per 100'000 person-years. Incidence was highest among children aged 2 years with 23,3 cases per 100'000 person-years (boys 25,8, girls 20,7). Incidence was lowest in 9 year olds with 10,4 cases per 100'000 person-years (boys 11,5, girls 9,3) (**Figure 5** shows crude incidence rates in Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1997-2016; 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 2007-2016: 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**	**665**	**33,8**	**1,6**	**4,8**	**5,5**
	a. Lymphoid leukaemias	538	80,9	1,5	4,7	4,5
	b. Acute myeloid leukaemias	76	11,4	1,7	5,7	0,6
	c. Chronic myeloproliferative diseases	12	1,8	2,0	11,3	0,1
	d. Myelodysplastic syndrome and other myeloproliferative diseases	31	4,7	2,4	7,0	0,3
	e. Unspecified and other specified leukaemias	8	1,2	0,6	4,4	0,1
II	**Lymphomas and reticuloendothelial neoplasms**	**216**	**11,0**	**1,8**	**11,3**	**1,8**
	a. Hodgkin lymphomas	99	45,8	0,9	12,6	0,8
	b. Non-Hodgkin lymphomas (except Burkitt lymphoma)	60	27,8	2,5	8,9	0,5
	c. Burkitt lymphoma	54	25,0	9,8	8,2	0,4
	d. Miscellaneous lymphoreticular neoplasms	3	1,4	NA	1,6	0,0
	e. Unspecified lymphomas	0	NA	NA	NA	NA
III	**CNS and miscellaneous intracranial and intraspinal neoplasms**	**436**	**22,1**	**1,0**	**6,8**	**3,6**
	a. Ependymomas and choroid plexus tumor	47	10,8	1,1	3,6	0,4
	b. Astrocytomas	190	43,6	1,0	6,8	1,6
	c. Intracranial and intraspinal embryonal tumors	77	17,7	1,0	6,1	0,6
	d. Other gliomas	51	11,7	1,2	6,9	0,4
	e. Other specified intracranial and intraspinal neoplasms	62	14,2	1,1	10,1	0,5
	f. Unspecified intracranial and intraspinal neoplasms	9	2,1	0,8	6,6	0,1
IV	**Neuroblastoma and other peripheral nervous cell tumours**	**139**	**7,1**	**1,0**	**1,6**	**1,2**
	a. Neuroblastoma and ganglioneuroblastoma	138	99,3	0,9	1,6	1,1
	b. Other peripheral nervous cell tumours	1	0,7	NA	5,6	0,0
V	**Retinoblastoma**	**42**	**2,1**	**0,8**	**0,8**	**0,3**
VI	**Renal tumours**	**93**	**4,7**	**0,8**	**3,3**	**0,8**
	a. Nephroblastoma and other nonepithelial renal tumours	88	94,6	0,8	3,2	0,7
	b. Renal carcinomas	5	5,4	0,7	8,5	0,0
	c. Unspecified malignant renal tumours	0	NA	NA	NA	NA
VII	**Hepatic tumours**	**20**	**1,0**	**2,3**	**2,4**	**0,2**
	a. Hepatoblastoma	18	90,0	2,6	2,1	0,1
	b. Hepatic carcinomas	2	10,0	1,0	11,5	0,0
	c. Unspecified malignant hepatic tumours	0	NA	NA	NA	NA
VIII	**Malignant bone tumours**	**82**	**4,2**	**0,7**	**11,8**	**0,7**
	a. Osteosarcomas	42	51,2	0,7	11,7	0,3
	b. Chondrosarcomas	2	2,4	1,0	14,0	0,0
	c. Ewing tumor and related sarcomas of bone	37	45,1	0,9	11,0	0,3
	d. Other specified malignant bone tumours	0	NA	NA	NA	NA
	e. Unspecified malignant bone tumours	1	1,2	NA	14,7	0,0
IX	**Soft tissue and other extraosseous sarcomas**	**137**	**7,0**	**1,1**	**7,2**	**1,1**
	a. Rhabdomyosarcomas	75	54,7	1,0	4,5	0,6
	b. Fibrosarcomas, peripheral nerve sheath tumours, and other fibrous neoplasms	8	5,8	3,0	12,2	0,1
	c. Kaposi sarcoma	0	NA	NA	NA	NA
	d. Other specified soft tissue sarcomas	41	29,9	0,9	10,6	0,3
	e. Unspecified soft tissue sarcomas	13	9,5	2,3	8,0	0,1
X	**Germ cell tumors, trophoblastic tumors, and neoplasms of gonads**	**59**	**3,0**	**1,0**	**6,3**	**0,5**
	a. Intracranial and intraspinal germ cell tumours	17	28,8	1,4	11,1	0,1
	b. Malignant extracranial and extragonadal germ cell tumours	21	35,6	0,8	0,1	0,2
	c. Malignant gonadal germ cell tumours	20	33,9	1,0	11,1	0,2
	d. Gonadal carcinomas	0	NA	NA	NA	NA
	e. Other and unspecified malignant gonadal tumours	1	1,7	NA	0,8	0,0
XI	**Other malignant epithelial neoplasms and malignant melanomas**	**77**	**3,9**	**0,6**	**12,0**	**0,6**
	a. Adrenocortical carcinomas	4	5,2	0,3	5,1	0,0
	b. Thyroid carcinomas	14	18,2	0,4	13,0	0,1
	c. Nasopharyngeal carcinomas	2	2,6	1,0	13,6	0,0
	d. Malignant melanomas	11	14,3	0,4	12,7	0,1
	e. Skin carcinomas	4	5,2	3,0	6,7	0,0
	f. Other and unspecified carcinoma	42	54,5	0,6	11,7	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	NA	0,0	0,0
Total (not including Langerhans cell histiocytosis)		**1969**	**100,0**	**1,2**	**6,2**	**16,3**
	Langerhans cell histiocytosis	59	2,9	1,6	6,9	0,5
Total (including Langerhans cell histiocytosis)		**2028**	**100,0**	**1,2**	**6,2**	**16,8**

* Incidence: newly diagnosed tumours in a one years time period per 100'000 persons (person-years); NA: not applicable

Swiss residents; age at diagnosis 0-14 years, period of diagnosis 2007-2016, all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=2028

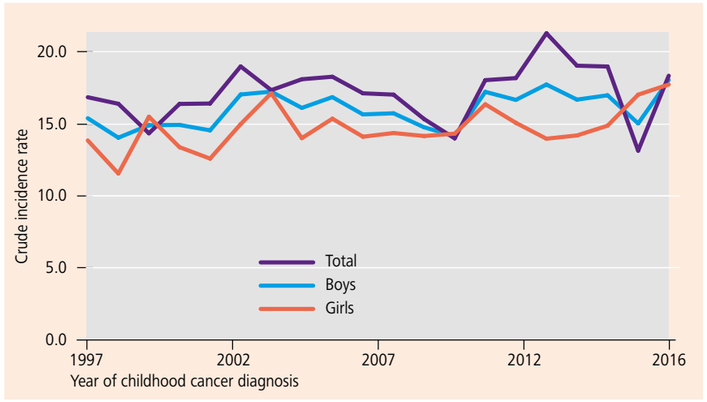


Figure 5
Crude incidence rate (per 100,000 person-years) in Switzerland, by sex and year of diagnosis for the last 20 years (1997-2016)

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 1997-2016; all diagnoses (ICCC-3 but not including Langerhans cell histiocytosis); N=3883

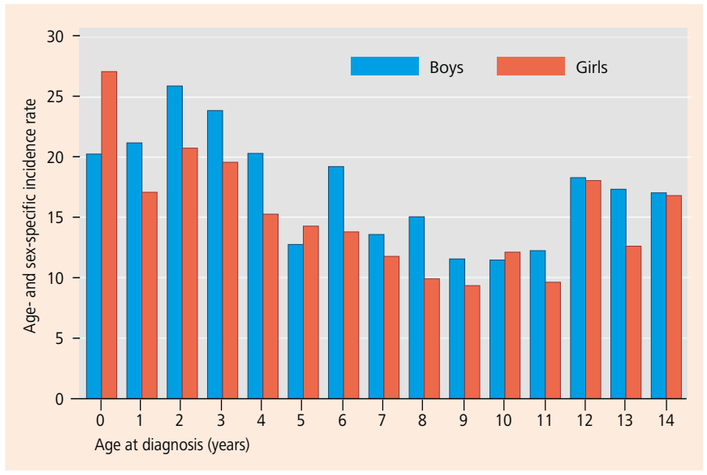


Figure 6
Age- and sex-specific incidence rates (per 100,000 person-years) in Switzerland for the last 10 years

Swiss residents; age at diagnosis 0-14 years; period of diagnosis 2007-2016; all diagnoses (ICCC-3 but not including Langerhans cell histiocytosis); N=1969

3.4 Swiss residents aged 15-20 years at diagnosis (N=558)

Table 6 describes the tumours registered in the last ten years (2007-2016) diagnosed in adolescent patients (aged 15-20 years at diagnosis, N=558). 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 2007-2016: 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**	**68**	**12,3**	**1,5**	**16,7**
	a. Lymphoid leukaemias	37	54,4	2,4	16,2
	b. Acute myeloid leukaemias	15	22,1	0,9	17,6
	c. Chronic myeloproliferative diseases	8	11,8	0,6	17,9
	d. Myelodysplastic syndrome and other myeloproliferative diseases	8	11,8	1,7	16,7
	e. Unspecified and other specified leukaemias	0	NA	NA	NA
II	**Lymphomas and reticuloendothelial neoplasms**	**142**	**25,6**	**0,9**	**16,9**
	a. Hodgkin lymphomas	94	66,2	0,8	16,8
	b. Non-Hodgkin lymphomas (except Burkitt lymphoma)	40	28,2	1,2	17,0
	c. Burkitt lymphoma	6	4,2	2,0	18,0
	d. Miscellaneous lymphoreticular neoplasms	1	0,7	NA	16,6
	e. Unspecified lymphomas	1	0,7	NA	15,3
III	**CNS and miscellaneous intracranial and intraspinal neoplasms**	**79**	**14,2**	**1,1**	**16,8**
	a. Ependymomas and choroid plexus tumor	8	10,1	3,0	18,3
	b. Astrocytomas	21	26,6	0,8	17,2
	c. Intracranial and intraspinal embryonal tumors	16	20,3	1,3	16,5
	d. Other gliomas	11	13,9	0,8	16,8
	e. Other specified intracranial and intraspinal neoplasms	20	25,3	1,2	16,6
	f. Unspecified intracranial and intraspinal neoplasms	3	3,8	2,0	16,8
IV	**Neuroblastoma and other peripheral nervous cell tumors**	**1**	**0,2**	**NA**	**16,3**
	a. Neuroblastoma and ganglioneuroblastoma	1	100,0	NA	16,3
	b. Other peripheral nervous cell tumors	0	NA	NA	NA
V	**Retinoblastoma**	**0**	**NA**	**NA**	**NA**
VI	**Renal tumors**	**6**	**1,1**	**5,0**	**16,9**
	a. Nephroblastoma and other nonepithelial renal tumors	2	33,3	NA	16,0
	b. Renal carcinomas	4	66,7	3,0	17,5
	c. Unspecified malignant renal tumors	0	NA	NA	NA
VII	**Hepatic tumors**	**2**	**0,4**	**NA**	**19,4**
	a. Hepatoblastoma	0	NA	NA	NA
	b. Hepatic carcinomas	2	100,0	NA	19,4
	c. Unspecified malignant hepatic tumors	0	NA	NA	NA
VIII	**Malignant bone tumors**	**49**	**8,8**	**1,5**	**16,2**
	a. Osteosarcomas	32	65,3	1,7	16,2
	b. Chondrosarcomas	2	4,1	1,0	16,4
	c. Ewing tumor and related sarcomas of bone	15	30,6	1,1	15,8
	d. Other specified malignant bone tumors	0	NA	NA	NA
	e. Unspecified malignant bone tumors	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**	**40**	**7,2**	**1,1**	**16,9**
	a. Rhabdomyosarcomas	12	30,0	1,0	16,2
	b. Fibrosarcomas, peripheral nerve sheath tumors, and other fibrous neoplasms	5	12,5	1,5	15,8
	c. Kaposi sarcoma	0	NA	NA	NA
	d. Other specified soft tissue sarcomas	18	45,0	1,0	18,8
	e. Unspecified soft tissue sarcomas	5	12,5	1,5	17,2
X	**Germ cell tumors, trophoblastic tumors, and neoplasms of gonads**	**52**	**9,4**	**3,0**	**17,9**
	a. Intracranial and intraspinal germ cell tumors	7	13,5	NA	17,2
	b. Malignant extracranial and extragonadal germ cell tumors	0	NA	NA	NA
	c. Malignant gonadal germ cell tumors	40	76,9	3,4	18,3
	d. Gonadal carcinomas	4	7,7	0,3	15,8
	e. Other and unspecified malignant gonadal tumor	1	1,9	NA	15,7
XI	**Other malignant epithelial neoplasms and malignant melanomas**	**113**	**20,4**	**0,5**	**18,5**
	a. Adrenocortical carcinomas	0	NA	NA	NA
	b. Thyroid carcinomas	31	27,4	0,2	18,4
	c. Nasopharyngeal carcinomas	3	2,7	2,0	19,9
	d. Malignant melanomas	31	27,4	0,8	18,9
	e. Skin carcinomas	10	8,8	1,5	19,0
	f. Other and unspecified carcinoma	38	33,6	0,5	18,0
XII	**Other and unspecified malignant neoplasms**	**3**	**0,5**	**2,0**	**17,4**
	a. Other specified malignant tumors	3	100,0	2,0	17,4
	b. Other unspecified malignant tumors	0	NA	NA	NA
Total (not including Langerhans cell histiocytosis)		**555**	**100,0**	**1,1**	**17,2**
	Langerhans cell histiocytosis	3	0,5	2,0	17,0
Total (including Langerhans cell histiocytosis)		**558**	**100,0**	**1,1**	**17,2**

Swiss residents; age at diagnosis 15-20 years, period of diagnosis 2007-2016, all diagnoses (ICCC-3 or Langerhans cell histiocytosis); N=558

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 variation of childhood cancer risk in Switzerland and associations with traffic-related air pollution	Spycher BD	Swiss Cancer Research (KFS-4012-08-2016)	01.2017-12.2018
2	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
3	The spatial epidemiology of childhood cancer in Switzerland	Spycher BD	Swiss Cancer Research (KFS-3515-08-2014)	01.2014-12.2016
4	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
5	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
6	Childhood cancer and vicinity of residence to petrol stations and roads: census-based nationwide cohort study (PETROL)	Kuehni CE	Federal Office of Public Health (10.002946)	06.2010-02.2013
7	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 Kuehni CE, Angst R Kuehni CE, Bergstraesser E Kuehni CE Von der Weid NX, Kuehni CE Von der Weid NX, Kuehni CE Kuehni CE	Stiftung zur Krebsbekämpfung 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	01.2017-12.2017 01.2012-12.2012 08.2010-07.2011 04.2009-03.2010 07.2008-06.2010 01.2006-10.2008 since 2006
2	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
3	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
4	Risk of cancer and long-term mortality in children treated with growth hormone: Swiss participation in the EU FP7 project (SAGhE)	Mullis P, Kuehni CE Mullis P Mullis P, Kuehni CE	Swiss Cancer League (KLS-2948-02-2012) EU (FP-HEALTH-F2-2009-223497) Swiss Cancer League (KLS-02586-02-2010)	07.2012-12.2013 04.2011-03.2014 07.2010-12.2012
5	Mortality after cancer in childhood and adolescence	Kuehni CE Kuehni CE	Swiss National Science Foundation (PDFMP3_141775) Swiss Bridge	08.2012-08.2015
6	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

No	Project name (continued)	Senior investigator	Funding sources	Study period
7	Pulmonary dysfunction after childhood cancer: diagnosing early stage disease	Kuehni CE	Swiss Cancer Research (KFS-4157-02-2017)	09.2017-08.2020
8	Lung problems after childhood cancer: Implementation of a structured follow-up care in Switzerland	Sommer G	Kinderkrebs Schweiz	06.2017-05.2018
9	Pulmonary late-effects in long-term childhood cancer survivors – Development of guidelines for follow-up care	Sommer G, Goutaki M	Cancer League Bern Lung League Bern	01.2017-02.2018
10	Cardiovascular disease after childhood cancer: diagnosing early stage disease	Von der Weid NX, Kuehni CE	Swiss Cancer League (KLS-3886-02-2016)	01.2017-12.2019
11	Improving follow-up care of childhood cancer: implementation of screening for psychological distress	Michel G, Scheinemann K	Krebsforschung Schweiz (KFS-3955-08-2016)	04.2017-03.2020
12	Needs for psychosocial care after childhood cancer – A mixed methods study	Michel G	Krebsforschung Schweiz (HSR-4080-11-2016)	06.2017-05.2019
13	Psychological late effects in long-term childhood cancer survivors – Development of guidelines for follow-up care	Michel G	Krebsliga Zentralschweiz	11.2015-10.2017
14	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
15	Effectiveness of transition from paediatric to adult care after childhood cancer	Michel G	Swiss Cancer League (KFS-02631-08-2010)	04.2011-04.2014
16	Parents of long-term childhood cancer survivors	Michel G	Swiss National Science Foundation (100019_153268/1) Kinderkrebshilfe Schweiz	since 2013
17	Fertility after Chemo- and Radiotherapy in Childhood and Adolescence, FeCt – Multicentre	Michel G	Kinderkrebshilfe Schweiz	since 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 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;
- Whether cancer risks in children are associated with socio-economic, family or perinatal exposures;
- The spatial and spatio-temporal distribution of childhood cancer cases in order to identify potential environmental risk factors.

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 NO2 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 investigating spatial and spatio-temporal clustering or identifying areas of higher risk (disease mapping) 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] and this clustering was associated with the TEL-AML1 (ETV6-RUNX1) cytogenetic subtype [Kreis-2017]. In contrast, we found little evidence of purely spatial clustering for childhood leukaemia [Konstantinoudis-2017].

B, Ongoing studies: In ongoing studies we are investigating whether: i) Childhood cancer is associated with increased air concentrations of benzene and NO2; ii) Childhood leukaemia is associated with perinatal characteristics (including parental age, birth order, age difference to next older sibling, and birth weight); iii) There is spatial clustering of childhood cancers other than leukaemia; and iv) There are specific areas of increased risk of childhood cancers in Switzerland (disease mapping). 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

Childhood cancer is the most common disease-related cause of death in childhood in the western world. Thanks to therapeutic improvements in the past 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, heart and lung disease, hearing loss, and infertility. These adverse late effects may impact 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 including the national Swiss Childhood Cancer Survivor Study (SCCSS), prospective, clinical studies on lung and cardiovascular diseases, and a study on cause-specific long-term mortality.

Aims

The 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.
- To investigate and improve follow-up care after childhood cancer among long-term survivors.

Methods

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

Study population: Eligible are all individuals, who have been diagnosed with cancer at age <21 years, who survived at least five years, were alive at the time of the study, and who were Swiss residents at time of diagnosis.

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. A second questionnaire is sent to participating survivors to find out whether their health has changed over time. We invite subgroups of survivors for clinical investigations to paediatric oncology centres to investigate their lung and heart functions and we collect saliva and urine samples for genetic and metabolic analyses. Additionally, we collect data from municipal population registries to obtain vital status and date of death, and Swiss mortality statistics to obtain causes of death. This broad approach makes it possible to investigate prevalence and incidence of adverse late effects in Swiss survivors and to identify predictors for their occurrence.

Response rate: For the SCCSS questionnaire survey, we contacted 4140 five-years survivors aged 0-<20 years at diagnosis, 2876 (70%) completed our questionnaire. Among the participating survivors, we contacted 1586 survivors with a second questionnaire, and currently 804 (51%) survivors completed the second questionnaire. This survey is still ongoing.

We also contacted 1522 siblings of childhood cancer survivors, of which 866 (57%) participated.

Current status

A, Recent findings

These ongoing studies provide the first national data on adverse late effects, health behaviour, survival and long-term mortality, and causes for mortality after childhood and adolescence cancer in Switzerland. We analyse and publish our findings continuously. Previous publications reported on health-related quality of life, education, cognitive problems, partnership, income, physical activity, lung disease, cardiovascular disease, hearing loss, nutrition, overweight, survival, and mortality. Our findings will help to identify patients who are at great risk for late effects, to adjust therapies, and to develop tailored follow-up programs for survivors.

Health-related quality of life (HRQoL): We also showed that survivors achieved similar educational levels than the general population [Kuehni-2012]. Survivors younger than 20 years were more likely to report cognitive problems than their siblings [Wengenroth-2015]. We found lower personal income in survivors than in siblings [Wengenroth-2016]. However, survivors' personal income may increase in a later stage, as treatment pushes back educational training and may cause them to start working later than their peers. Survivors are less likely to be married or in a life partnership than peers [Wengenroth-2014], this might be because survivors take longer to reach their final education achievement and this might encourage survivors to delay marriage.

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 daily living activities but 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 overall poor [Belle-2016].

Hearing loss: We found that the burden of hearing loss as a late effect after ototoxic cancer treatment has stabilized in recently treated survivors, suggesting that survivors have benefited from new treatment regimens that use less ototoxic radiation and carefully dosed platinum compounds [Weiss-2017]. We also found that questionnaires are useful to assess hearing in large cohorts of childhood cancer survivors, but they underestimate mild and unilateral hearing loss. [Weiss-2017].

Lung diseases: We found that five-year survival of children diagnosed with cancer in Switzerland improved from 64% in 1976-1983 to 88% in 2004-2013, but there is room for further improvement. Survival rates varied by type of clinical treatment, language region and nationality. All paediatric cancer patients should be referred to a specialised paediatric cancer centre [Schindler-2017].

Mortality: We found that five-year survivors of childhood cancers suffer from an elevated mortality 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) lung diseases; ii) cardiovascular diseases; iii) hearing loss; and v) dietary habits and overweight. In addition, we investigate how follow-up care is performed in patients at risk for lung diseases and we actively participate in the development and implementation of clinical guidelines for follow-up care in Switzerland. We are currently setting up a project for the collection of germline DNA of all childhood cancer patients for pharmacogenetic studies. Furthermore, we collaborate in international studies (see International collaborations).

Contact

The research team consists of Claudia Kuehni, Fabiën Belle, Rahel Kasteler, Rahel Kuonen, Christina Schindera, Grit Sommer, Nicolas Waespe, 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 to 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

And 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, cardiovascular 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:

Currently, we are collaborating in two ongoing studies:

PanCareSurFup (PanCare childhood and adolescent cancer survivor care and follow-up studies; http://www.pancare-surfup.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 five-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]. Three publications have been submitted in 2017 an 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 304 survivors at risk for hearing loss and collected their hearing tests. Among the 304 survivors, we could contact 221 survivors for the collection of saliva samples and153 survivors provided their saliva sample for the analysis of genetic risk factors of hearing loss. We contributed questionnaire data from 1594 survivors 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 experts worldwide and the International Guideline Harmonization Group (IGHG, http://www.ighg.org/), we write systematic reviews and 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)
  - Psychosocial WG leaders: Katie Devine (USA), Martha Grootenhuis (NL)
  - Metabolic syndrome and obesity
- ***Overweight/obesity***
  - WG leaders: Kevin Oeffinger (USA), Emily Tonorezos (USA)
- ***Hypothalamic-Pituitary disorders***
  - Chairs: Hanneke van Santen (NL), Wassim Chemaitilly (US)

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, Fabiën Belle, 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, adolescents 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 group aims to:

- Describe follow-up care models available across Europe, and preferences for a follow-up model among Swiss childhood, adolescent 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 are lacking 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]. Parents' preferred model of care was paediatric oncologist-led follow-up or follow-up provided by a multidisciplinary team [Vetsch-2017]. Furthermore, parents rated clinical reasons to attend follow-up more important than supportive reasons [Vetsch-2017].

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, as well as of Claudia Kuehni, and Nicolas von der Weid.

5. Publications of the Swiss Childhood Cancer Registry

All articles published using SCCR data from January 2007 – July 2017 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)

2017

1. Kasteler R, Weiss A, Schindler M, Sommer G, Latzin P, von der Weid N, Ammann R, Kuehni CE, Swiss Pediatric Oncology G. Long-term pulmonary disease among Swiss childhood cancer survivors. Pediatr Blood Cancer. 2017; *doi: 10.1002/pbc26749.*
2. Mader L, Vetsch J, Christen S, Baenziger J, Roser K, Dehler S, Michel G. Education, employment and marriage in long-term survivors of teenage and young adult cancer compared with healthy controls. Swiss Med Wkly. 2017; 147:314419.
3. Bonaventure A, Harewood R, Stiller CA, Gatta G, Clavel J, Stefan DC, Carreira H, Spika D, Marcos-Gragera R, Peris-Bonet R, Pineros M, Sant M, Kuehni CE, Murphy MFG, Coleman MP, Allemani C, Group CW. Worldwide comparison of survival from childhood leukaemia for 1995-2009, by subtype, age, and sex (CONCORD-2): a population-based study of individual data for 89 828 children from 198 registries in 53 countries. Lancet Haematol. 2017; 4(5):e202-e17.
4. Kreis C, Lupatsch JE, Niggli F, Egger M, Kuehni CE, Spycher BD, Swiss Paediatric Oncology G, Swiss National Cohort Study G. Space-Time Clustering of Childhood Leukemia: Evidence of an Association with ETV6-RUNX1 (TEL-AML1) Fusion. *PLoS One, 2017. 12(1): p. e0170020.*
5. Konstantinoudis G, Kreis C, Ammann RA, Niggli F, Kuehni CE, Spycher BD, Swiss Paediatric Oncology G, the Swiss National Cohort Study G. Spatial clustering of childhood leukaemia in Switzerland: A nationwide study. *Int J Cancer, 2017. Epub ahead of print. doi: 10.1002/ijc.30832.*
6. Vetsch J, Rueegg CS, Mader L, Bergstraesser E, Diezi M, Kuehni C, Michel G. Parents' preferences for the organization of long-term follow-up of childhood cancer survivors. *Eur J Cancer Care 2017;* doi: *10.1111e12649.*
7. Schindler M, Belle FN, Grotzer MA, von der Weid NX, Kuehni CE, Swiss Paediatric Oncology G. Childhood cancer survival in Switzerland (1976-2013): Time-trends and predictors. *Int J Cancer. 2017; 140:62-74.*
8. Weiss A, Sommer G, Kuonen R, Scheinemann K, Grotzer M, Kompis M, Kuehni CE, Swiss Paediatric Oncology G. Validation of questionnaire-reported hearing with medical records: A report from the Swiss Childhood Cancer Survivor Study. *PLoS One. 2017; 12(3):e0174479.*
9. Weiss A, Sommer G, Kasteler R, Scheinemann K, Grotzer M, Kompis M, Kuehni CE, Swiss Paediatric Oncology G. Long-term auditory complications after childhood cancer: A report from the Swiss Childhood Cancer Survivor Study. *Pediatr Blood Cancer. 2017; 64(2):364-373.*
10. Rueegg CS, Gianinazzi ME, Michel G, Zwahlen M, von der Weid NX, Kuehni CE, and the Swiss Paediatric Oncology G. No evidence of response bias in a population-based childhood cancer survivor questionnaire survey - Results from the Swiss Childhood Cancer Survivor Study. *Plos ONE. 2017; 12(5):e0176442.*
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13. Mader L, Roser K, Baenziger J, Tinner EM, Scheinemann K, Kuehni CE, Michel G, Swiss Paediatric Oncology G. Household income and risk-of-poverty of parents of long-term childhood cancer survivors. *Pediatr Blood Cancer. 2017; 64(8).*

2016

14. Adel Fahmideh M, Lavebratt C, Schuz J, Roosli M, Tynes T, Grotzer MA, Johansen C, Kuehni CE, Lannering B, Prochazka M, Schmidt LS, Feychting M. Common genetic variations in cell cycle and DNA repair pathways associated with pediatric brain tumor susceptibility. *Oncotarget. 2016; 7(39):63640-50.*
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18. 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.*
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childhood leukaemia and population growth in Swiss municipalities. *Eur J Epidemiol. 2016d.*

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2015

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2013

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2009

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2007

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5.2 Editorials, commentaries and author replies (Peer reviewed journals)

2015

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2012

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2006

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5.3 Reviews (Peer reviewed journals)

2015

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2012

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2008

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5.4 Publications (other journals)

Schweizer Krebsbulletin

2016

100. Lupatsch JE, Kreis C, Niggli F, Kuehni CE, Spycher B. 2016. Ursachen von Krebs bei Kindern: Was verrät der Wohnort? Schweizer Krebsbulletin 2016a; 36(01): 29-33.

2014

101. Wengenroth L, Schindler M, Kuonen R, Kuehni CE. Krebs als Kind oder Teenager: das Leben danach. Schweizer Krebsbulletin 2014; 4: 292-295.
102. Michel G, von der Weid NX. Nachsorge nach Krebs im Kindesalter – Pläne für die Schweiz. Schweizer Krebsbulletin 2014; 4: 296-298

2013

103. Kuehni CE, Mitter V, Niggli F, von der Weid NX. Die Rolle des Kinderkrebsregisters unter dem geplanten Krebsregistrierungsgesetz: Chancen und Risiken. Schweizer Krebsbulletin 2013; 3:213-216.

2012

104. Niggli F, Kuehni CE, Lamontagne-Müller S. Seltene Krebserkrankungen – das tägliche Brot der pädiatrischen Onkologie. Schweizer Krebsbulletin. 2012; 4. 309-10.
105. Michel G. Nachsorge nach Krebs im Kindesalter. Schweizer Krebsbulletin. 2012; 3: 212-213.

2010

106. Kuehni CE. The Swiss Childhood Cancer Registry: from causes to outcomes. Schweizer Krebsbulletin. 2010; 2:129-130.

2009

107. Kuehni CE, Feller M, Egger M. Response to: Sufficient statistical power for CANUPIS? Bulletin suisse du cancer. 2009; 4.09:301.

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108. Kuehni CE, von der Weid NX, Hengartner H, Niggli F, Röösli M, Huss A, Feller M, Egger M. CANUPIS – Childhood Cancer and Nuclear Power Plants in Switzerland. Schweizer Krebsbulletin. 2008; 28: 264-266.
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Other

2016

110. Weiss A, Kuehni CE, Michel G, von der Weid NX. 40 Jahre Plattform für Forschung und Monitoring. Das Schweizer Kinderkrebsregister. *info@onkologie. 2016; (05):40-42.*

2013

111. Mitter V, Michel G. Krebs bei Kindern. Ein Überblick aus dem Schweizer Kinderkrebsregister. *Onkologiepflege 1; 5-8.*
112. Ruegg CS, Gianinazzi ME, Michel G. Psychosoziale Spätfolgen nach Kinderkrebs – Eine Langzeitstudie des Schweizer Kinderkrebsregisters. *Newsletter Schweizerische Gesellschaft für Psychoonkologie. 21; 5-8.*
113. Kuehni CE, Michel G, Egger M, Zwahlen M, Beck Popovic M, Nigglie F, von der Weid NX. Das Schweizer Kinderkrebsregister: Erfahrungen als nationales Krebsregister. *Schweizerische Ärztezeitung 2013; 94: 327.*
114. Kuehni CE, Niggli FK. Endlich ein nationales Krebsregistrierungsgesetz für Kinder und Erwachsene. *Schweizerische Ärztezeitung 2013; 94: 160.*

2011

115. Michel G. Nachsorge nach Krebs im Kindesalter – ein neues Feld für Pflege?. *Onkologiepflege 2011; 3: 20-23.*

2008

116. Kuehni CE, von der Weid NX. Das Schweizer Kinderkrebsregister als erstes nationales Krebsregister: Information der Ärzteschaft zur neuen Datenschutzsituation. Schweizerische *Aerztezeitung. 2008; 89:117-9.*
117. Kuehni CE, von der Weid NX. Das Schweizer Kinderkrebsregister als erstes nationales Krebsregister: Information der Ärzteschaft zur neuen Datenschutzsituation. *Paediatrica. 2008; 19:53-5.*
118. von der Weid NX, Kuehni CE. Le Registre Suisse du Cancer de l'Enfant: premier Registre du Cancer national. Information de la communauté médicale quant à la nouvelle situation concernant la protection des données. *Paediatrica. 2008; 19:50-2.*

2007

119. Kuehni CE. Children's health and the environment. A global perspective (Book review). *Paediatrica 2007; 15:13-28.*

5.5 Reports

Annual Reports SCCR

2016

120. Pfeiffer V, Redmond S, Kuonen R, Sommer G, Schindler M, Singh P, Michel G, Kuehni CE, The Swiss Childhood Cancer Registry. Annual Report 2014/2015. Berne: Dept. of Social and Preventive Medicine, University of Bern; June 2016.

2015

121. Schindler M, Mitter V, Pfeiffer V, Redmond S, Wölfli P, Kuonen R, Sommer G, Spring M, Singh P, Michel G, Kuehni CE, The Swiss Childhood Cancer Registry. Annual Report 2013/2014. Berne: Dept. of Social and Preventive Medicine, University of Bern; March 2015.

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122. Mitter V, Michel G, Wölfli P, Gianinazzi M, Ruegg CS, Sommer G, Hau E, Kuehni CE, The Swiss Childhood Cancer Registry. Annual Report 2011/2012. Berne: Dept. of Social and Preventive Medicine, University of Bern; Feb 2013.

2011

123. Mitter V, Michel G, Strippoli MPF, Rebholz CE, Rueegg CS, Viehmann G, Reck M, Niggli F, Hengartner H, von der Weid NX, Kuehni CE. The Swiss Childhood Cancer Registry. Annual Report 2009/2010. Bern: Dept. of Social and Preventive Medicine, University of Bern; April 2011.

2009

124. Kuehni CE, Michel G, Pyrlic M, Strippoli MP, Adam M, Rebholz C, Rueegg C, Viehmann G, Reck M, Niggli F, Hengartern H, von der Weid N. The Swiss Childhood Cancer Registry. Annual Report 2007/2008. Berne: Dept. of Social and Preventive Medicine, University of Bern; June 2009.

2008

125. Michel G, von der Weid NX, Adam M, Rebholz G, Zwahlen M, Kuehni CE. The Swiss Childhood Cancer Registry. Annual Report 2005/2006. Berne: Dept. Of Social and Preventive Medicine, University of Bern; May 2007.

2005

126. Kuehni CE, Michel G, Sturdy M, Redmond S, Zwahlen M, von der Weid N. The Swiss Childhood Cancer Registry. *Annual Report 2004. Bern: Dept. of Social and Preventive Medicine, University of Bern; December 2005.*

Other Reports

2016

127. Arndt V, Feller A, Hauri D, Heusser R, Junker C, Kuehni CE, Lorenz M, Pfeiffer V, Roy E, Schindler M. Schweizerischer Krebsbericht 2015 – Stand der Entwicklungen. Bundesamt für Statistik (BFS); Neuchâtel 2016.

2011

128. Wyss N, Pury P, Strippoli MPF, Lutz JM, Bouchardy C, Kuehni CE, Junker C. Krebs in der Schweiz – Stand und Entwicklung von 1983 bis 2007. Bundesamt für Statistik (BFS); Neuchâtel 2011.

2005

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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.

Schweizer Kinderkrebsregister
Registre Suisse du Cancer de l'Enfant
Registro Svizzero dei Tumori Pediatrici
Swiss Childhood Cancer Registry

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Gruppo d'Oncologia Pediatrica Svizzera
Swiss Paediatric Oncology Group