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

UNIVERSITÄT BERN

Jahresbericht
Rapport annuel
Relazione annuale

Annual Report 2009/2010

Swiss Childhood Cancer Registry
Annual Report 2009/2010

Vera Mitter
Gisela Michel
Marie-Pierre Strippoli
Corina Rüegg
Cornelia Rebholz
Martin Feller
Eva Hau
Marianne Reck
Claudia Kuehni

For the SPOG
Felix Niggli
Heinz Hengartner
Maja Beck-Popovic
Nicolas von der Weid

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(PD Dr. med. Claudia Kuehni)

Address:
Institute of Social and Preventive Medicine
University of Bern
Finkenhubelweg 11
CH-3012 Bern
Switzerland

Tel.: +41 (0)31 631 56 70
Tel.: +41 (0)31 631 38 99
Fax: +41 (0)31 631 36 48
E-mail: kinderkrebsregister@ispm.unibe.ch

Homepage: www.childhoodcancerregistry.ch
Logo: Elsbeth Kuehni

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 in Switzerland. Since 1976, it registers new cancer diagnoses, clinical information, details on treatment and long term follow-up (survival, second tumours and late effects). With many associated research projects and through close collaboration with clinicians it contributes to understanding the causes of cancer in children, improving treatment and 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 and closely cooperates with the Swiss Paediatric Oncology Group (SPOG) and the National Institute for Cancer Epidemiology and Registration (NICER). All Swiss paediatric haematology-oncology centres report newly diagnosed cases to the registry and send annual updates on clinical follow-up afterwards. Since 2007, the SCCR systematically collects data from other sources such as the cantonal cancer registries, other hospitals, pathology laboratories and the Federal Statistical Office (FSO). As of 31st December 2009 data from 6099 cases have been registered.

The Federal Commission of Experts for Professional Secrecy in Medical Research (Eidgenössische Expertenkommission für das Berufsgeheimnis in der medizinischen Forschung) gave the SCCR a general authorization for collecting non-anonymised data.

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). It collaborates with childhood cancer registries throughout Europe, e.g. the German Childhood Cancer Registry in Mainz (GCCR) and the National Registry of Childhood Tumours UK in Oxford (NRCT).

This 4th annual report covers the routine analyses of all children diagnosed between 1st January 1976 and 31st December 2009. Data on children diagnosed in 2010 will be presented in the next annual report. Activities and projects of the SCCR are described for the years 2009 and 2010. In particular, this 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 2009 (routine analyses; **chapter 3**)
- a list of current research projects of the SCCR (**chapter 4**)
- a review of activities for the years 2009 and 2010 (**chapter 5**)
- a list of publications (**chapter 6**)
- abbreviations and appendix (**chapters 7 & 8**)

Our website (www.childhoodcancerregistry.ch) contains further information such as past annual reports.

We thank all the children with their families and all the adolescent or adult childhood cancer survivors for allowing us to collect their data. We also thank all the physicians and data managers of the Swiss Paediatric Oncology Group for their excellent collaboration. Our thanks also go to the cantonal cancer registries, NICER, the Federal Statistical Office (FSO), the Federal Office of Public Health (FOPH) and the pathology laboratories for their cooperation. Finally, we thank all our supporters for their generous contributions.

2 Organisation of the Swiss Childhood Cancer Registry

2.1 Team

The Swiss Childhood Cancer Registry (SCCR) is operated jointly by the Swiss Paediatric Oncology Group (SPOG) and the Institute of Social and Preventive Medicine (ISPM) at the University of Bern.

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

Finkenhubelweg 11, 3012 Bern
Tel.: +41 (0)31 631 56 70 / +41 (0)31 631 38 99
Fax: +41 (0)31 631 36 48
E-Mail: kinderkrebsregister@ispm.unibe.ch

Childhood cancer group		
PD Dr. med. Claudia Kuehni FMH Paediatrics, MSc Epidemiology	Head of SCCR *Overall responsibility*	kuehni@ispm.unibe.ch
Dr. Gisela Michel, PhD	Vice head of SCCR *Research project:* *Follow-up care after childhood and young adult cancer (CCFU)*	michel@ispm.unibe.ch

Swiss Childhood Cancer Registry		
Vera Mitter, MSc	Project management	vmitter@ispm.unibe.ch
Dr. med. Elisabeth Kiraly	Diagnostic coding	kiraly@ispm.unibe.ch
Marlen Spring	Data management	mspring@ispm.unibe.ch
Jeannine Kropf	Data management	jkropf@ispm.unibe.ch
Marianne Reck	Fundraising, communication	mreck@ispm.unibe.ch
Simone Constantin	Statistics	sconstantin@ispm.unibe.ch

Informatics and database support		
Gerrit Viehmann	Logistics, database support	gviehmann@ispm.unibe.ch
Malcolm Sturdy	Database support	sturdy@ispm.unibe.ch
Philipp Läuppi	Web-design, web-administration	plaeuppi@ispm.unibe.ch

Research projects		
Dr. med. Martin Feller	Childhood Cancer and Nuclear Power Plants in Switzerland (CANUPIS)	mfeller@ispm.unibe.ch
Dr. med. Eva Hau	PanCare SurFup	ehau@ispm.unibe.ch
Cornelia Rebholz, MSc Corina Rüegg, MSc Laura Wengenroth, MSc	PhD students in the Swiss Childhood Cancer Survivor Study (SCCSS)	crebholz@ispm.unibe.ch crueegg@ispm.unibe.ch lwengenroth@ispm.unibe.ch
Marie-Pierre Strippoli, MSc	Statistics, research fellow	strippol@ispm.unibe.ch
Dr. Grit Sommer, PhD Fatma Karabulut, MSc	Growth Hormone project “SAGhE”	gsommer@ispm.unibe.ch fkarabulut@ispm.unibe.ch

Swiss Paediatric Oncology Group (SPOG)

SPOG Office
Effingerstrasse 40, 3008 Bern
Tel.: +41 (0)31 389 91 89
Fax: +41 (0)31 389 92 00

SPOG Executive Board		
Prof. Dr. med. Felix Niggli	President	felix.niggli@kispi.uzh.ch
Dr. med. Heinz Hengartner	Vice president	heinz.hengartner@kispisg.ch
PD Dr. med. Maja Beck Popovic	Secretary	maja.beck-popovic@chuv.ch
PD Dr. med. Nicolas von der Weid	Past president	nicolas.von-der-weid@chuv.ch

SPOG Office in Bern		
Isabelle Lamontagne-Müller	Managing director	isabelle.lamontagne@spog.ch
Dr. Stefanie Lerch, PhD	Quality assurance	stefanie.lerch@spog.ch
Martina Peluso	Regulatory affairs	martina.peluso@spog.ch
Susanna Kumli	Central administration	susanna.kumli@spog.ch

Participating centres (haematology-oncology)		
	Head of Division	Local Data Manager
Aarau (Kinderklinik, Kantonsspital Aarau)	Dr. med. R. Angst	Dr. med. R. Angst
Basel (Universitätskinderspital beider Basel [UKBB])	Prof. Dr. med. T. Kühne (ad interim)	V. Stahel
Bern (Universitätsklinik für Kinderheilkunde, Inselspital)	Prof. Dr. med. K. Leibundgut	F. Julmy N. Beusch
Genève (Hôpital des Enfants, Hôpitaux Universitaires de Genève [HUG])	PD Dr. med. H. Ozsahin	M. Crouche
Lausanne (Service de Pédiatrie, Centre Hospitalier Universitaire Vaudois [CHUV])	PD Dr. med. M. Beck Popovic	Dr. med. R.-E. Garcia
Bellinzona (Reparto di Pediatria, Ospedale S. Giovanni, Bellinzona)	Dr. med. P. Brazzola	Dr. med. P. Brazzola
Luzern (Kinderspital, Kantonsspital Luzern)	PD Dr. med. J. Rischewski	Y. Bonetti
St.Gallen (Ostschweizer Kinderspital)	Dr. med. J. Greiner-Lang	F. Hochreutener
Zurich (Universitäts-Kinderklinik, Zürich)	Prof. Dr. med. F. Niggli Prof. Dr. med. M. Grotzer	H. Markiewicz A. Reinberger

2.2 General information

Inclusion criteria and data collection

The SCCR registers all children and adolescents aged 0 to 20 years diagnosed with:

- acute and chronic leukaemias, including myelodysplastic syndrome
- lymphomas
- solid malignancies
- central nervous system tumours (CNS), including benign tumours
- Langerhans cell histiocytosis (LCH) and other histiocytosis (type I–III)

Most children are treated in, and reported by one of the nine Swiss centres for paediatric oncology and haematology. Additional sources of information for incident cases are cantonal cancer registries, the Federal Statistical Office (FSO), pathology laboratories and smaller hospitals. The SCCR aims for complete registration of all children and adolescents up to the age of 20 years. Completeness has been largely achieved for children aged 0-15 years at diagnosis.[1] The quality of data is controlled and the date of death is validated against death certificates from the FSO. Children and adolescents who are not Swiss residents but come to Switzerland for diagnosis and treatment are registered, but excluded from the analyses of incidence and survival.

Follow-up data are extracted annually from patients' hospital records for the first 5 to 10 years after diagnosis. When follow-up in a clinic ends, long-term follow-up is maintained by direct contact to the patients using a questionnaire (see chapter 4: Project 4 - Swiss Childhood Cancer Survivor Study) and via data linkage with mortality records (FSO) and cantonal cancer registries.

In the nine paediatric haematology-oncology centres in Switzerland, local data managers complete forms for newly diagnosed cases, relapses, transplantations and clinical follow-up examinations. 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.

Clinical database

The currently used electronic database of the SCCR was set up in 2007. At present, the following information is collected:

- tumour diagnosis, date of diagnosis, type of cancer, histology, stage, metastases
- other diagnoses (relevant pre-existing conditions)
- clinical information and relevant laboratory data
- treatment (first study notification, treatment protocols, medication and dosages, radiotherapy, surgical interventions)
- follow-up data (changes of treatment, remissions, relapses, survival/death and cause of death)
- late effects
- treatment centres involved
- date of birth, sex, first language
- parental profession(s), parental date(s) of birth

1 Adam M, von der Weid NX, Michel G, Zwahlen M, Lutz JM, Probst-Hensch N, Niggli F, Kuehni CE. Access to specialized pediatric cancer care in Switzerland. Pediatric Blood & Cancer 2010; 54:721-7.

Administrative database

Since 2010, personal information on names and addresses is collected in a separate database. This is an important tool to support case registration and research projects that need an address history from birth to the date of diagnosis, or a current address. The address database supports the validation of addresses, patient nationality, and vital status via community registration offices. The address information is kept completely separate from clinical information. The following data are collected:

- patients' names, address at the time of diagnosis, address history and current address
- residence status and nationality at the time of diagnosis
- vital status and date of death

Tumour coding

The SCCR codes all tumours according to the following international classification systems (see appendix):

- International Classification of Childhood Cancer, third edition (ICCC-3)[2]
- International Statistical Classification of Diseases for Oncology, third edition (ICD-O-3)[3]
- International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10)[4]

In the annual report we use the main diagnostic groups of ICCC-3:

I. Leukaemias, II. Lymphomas, III. Central nervous system (CNS) neoplasms, IV. Neuroblastoma, V. Retinoblastoma, VI. Renal tumours, VII. Hepatic tumours, VIII. Malignant bone tumours, IX. Soft tissue sarcomas (STS), X. Germ cell tumours, XI. Other malignant epithelial neoplasms, XII. Other specified and unspecified malignant neoplasms. Langerhans cell histiocytosis (LCH), which is not contained in ICCC-3, is reported separately.

Completeness

The incidence of childhood cancers in the SCCR is comparable to the published incidence in Swiss cantonal cancer registries and in neighbouring countries (France, Germany and Italy).[5] In 2006-2008, we compared the SCCR data with datasets from the cantonal cancer registries (Basel, Geneva, Grisons and Glarus, Valais, St. Gallen and Appenzell, Ticino, Zurich). Overall for the time period from 1990 to 2004, we found that 22% of children registered in cantonal registries had not been registered in the SCCR.[6] Of these, 6% had been treated in a paediatric cancer centre belonging to SPOG, but had not been reported to the SCCR, and 16% had been treated in other hospitals, including paediatric hospitals and adult wards.

2 Steliarova-Foucher E, Stiller C, Lacour B, Kaatsch P. International Classification of Childhood Cancer, Third Edition. Cancer 2005; 103:1457-67.
3 World Health Organization. International Statistical Classification of Diseases for Oncology - Third Edition (ICD-O-3). Geneva: World Health Organization; 2000.
4 World Health Organization. International Statistical Classification of Diseases and Related Health Problems - Tenth Revision. Geneva: World Health Organization; 1993.
5 Michel G, von der Weid NX, Zwahlen M, Redmond S, Strippoli MPF, Kuehni CE. Incidence of childhood cancer in Switzerland: the Swiss Childhood Cancer Registry. Pediatric Blood & Cancer 2008; 50:46-51.
6 Adam M, von der Weid NX, Michel G, Zwahlen M, Lutz JM, Probst-Hensch N, Niggli F, Kuehni CE. Access to specialized pediatric cancer care in Switzerland. Pediatric Blood & Cancer 2010; 54:721-7.

During the period covered in this study, the proportion of cases not treated in a paediatric cancer centre decreased, from 24% in 1990-1993 to 7% in 2002-2004. All additional cases identified by this study have since been included, so that completeness of the SCCR is now more than 95%.

Based on these results, the SCCR changed its registration practice and now identifies cases from various sources, including regular data exchange with cantonal cancer registries, data collection from other hospitals or pathology laboratories and using information from mortality statistics (see chapter 5).

Data protection

In 2004, the SCCR received a special authorization (Sonderbewilligung) from the Swiss Federal Commission of Experts for Professional Secrecy in Medical Research.
In June 2007, this was replaced by a general authorization (Generelle Bewilligung), which permits the collection of data on cancer in children and adolescents throughout Switzerland by obtaining written, oral or silent consent. A copy of the document provided by the expert commission can be downloaded from our homepage,[7] together with explanations in French and German. At the time of diagnosis, all cases, treated in a Swiss paediatric oncology centre and their parents are informed by their treating physician about the childhood cancer registry. The patient has the right to stop transfer of non-anonymised data to the registry (veto power/possibility to opt out). Records of these cases are kept completely anonymised at all times. Information for cases is available from hospital brochures, hospital notice boards, parents and patients organisations. In the SCCR all case data are kept strictly confidential. Data with personal information (names, addresses) are stored separately from the clinical information.

In 2010 data protection measures of the SCCR were examined by the Federal Data Protection and Information Commissioner and the cantonal data protection officer of Bern. In collaboration with these authorities the data collection and data storage was revised and refined. The new procedures were approved by the Federal Commission of Experts for Professional Secrecy in Medical Research.

7 http://www.childhoodcancerregistry.ch/index.php?id=2451

Funding

The SCCR thanks the following supporters for their financial contributions towards the daily running and continuous development of the registry. Supporters of scientific research projects are listed in **Table 12** (page 34).

Supporters 2009/10

GDK Schweizerische Konferenz der kantonalen Gesundheitsdirektorinnen und -direktoren
CDS Conférence suisse des directrices et directeurs cantonaux de la santé
CDS Conferenza svizzera delle direttrici e dei direttori cantonali della sanità

nicer
National Institute for Cancer Epidemiology and Registration
Nationales Institut für Krebsepidemiologie und -registrierung
Institut National pour l'Épidémiologie et l'Enregistrement du Cancer
Istituto Nazionale per l'Epidemiologia e la Registrazione del Cancro

SPOG
Schweizerische Pädiatrische Onkologie Gruppe
Groupe d'Oncologie Pédiatrique Suisse
Gruppo d'Oncologia Pediatrica Svizzera
Swiss Paediatric Oncology Group

kinderkrebshilfe schweiz

Stiftung für krebskranke Kinder Regio Basiliensis

AMGEN

amarillo treuhand

interpharma ph

NOVARTIS

gsk GlaxoSmithKline

AXA winterthur
FINANZIELLE SICHERHEIT

confidas
TREUHAND AG

AstraZeneca

Celgene

Pfizer

Takeda
Takeda Pharma

Essex Chemie

Biotherapies for Life™ CSL Behring

3 Routine analyses covering cases diagnosed from 1976-2009

Overview

The section on routine analyses includes three chapters.

Chapter 3.1 describes the whole database, i.e. all children registered in the SCCR from 1st January 1976 till 31st December 2009, with a diagnostic code contained in ICCC-3 or a Langerhans cell histiocytosis (LCH), irrespective of the age at diagnosis. It includes adolescents aged 15 to 20 years. This age group is often treated in adult clinics and therefore its reporting and registration are incomplete in the SCCR. In addition, chapter 3.1 includes some information on children resident in other countries but diagnosed and treated in Switzerland.

Chapter 3.2 includes the core group of children aged 0-14 years and resident in Switzerland at the time of diagnosis. This is the age group usually covered in international publications therefore the tables and figures can be directly compared with data from other countries. Case registration in Switzerland is more than 95% complete for this age range, allowing the calculation of incidence and survival.

Chapter 3.3 describes cases reported by different centres belonging to SPOG, irrespective of the age at diagnosis and the country of residence.

3.1 Cases registered (N=6099)

Up to 31st December 2009, a total of 6099 cases with a tumour coded according to ICCC-3, or a Langerhans cell histiocytosis (LCH), have been registered in the SCCR. Of these, 5429 (89%) were Swiss residents at the time of diagnosis and 563 (9%) were foreign residents (**Table 1**). Due to the Jules Gonin Eye Hospital in Lausanne, which treated 201 of 293 cases of retinoblastoma, among retinoblastoma cases 56% (163/293) were foreign residents.

The SCCR started in 1976, initially with the registration of all cases participating in clinical trials. Since 1981, non-trial cases were also included, resulting in a significant increase in case numbers. There was a further increase in case registration in the early 1990's with the introduction of our electronic database (**Figure 1**). Since then, annual registration has remained stable. In the years 2005-2009, a total of 1117 new cases were registered, of whom 1011 were Swiss residents at the time of diagnosis (**Table 2**).

Table 1 – Total number of registered cases, by country of residence

Including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2009 (N=6099)

Country of residence	All ages		0-14 years		>14 years	
	n	%	n	%	n	%
1 Switzerland	5429	89.0	5000	88.8	429	91.7
2 Other countries	563	9.2	542	9.6	21	4.5
a Europe	420	6.9	406	7.2	14	3.0
Neighbouring countries*	287	4.7	274	4.9	13	2.8
Other European countries	133	2.2	132	2.3	1	0.2
b Middle East	8	0.1	8	0.1	0	0.0
c North Africa	82	1.3	76	1.3	6	1.3
d Other African countries	33	0.5	32	0.6	1	0.2
e Other countries	20	0.3	20	0.4	0	0.0
3 Country of residence missing	107	1.8	89	1.6	18	3.8
TOTAL	**6099**	**100.0**	**5631**	**100.0**	**468**	**100.0**

* Austria (N=10), France (N=71), Germany (N=58), Italy (N=111), Liechtenstein (N=37)

Figure 1 – Annual number of registered cases over time

Including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2009 (N=6099)

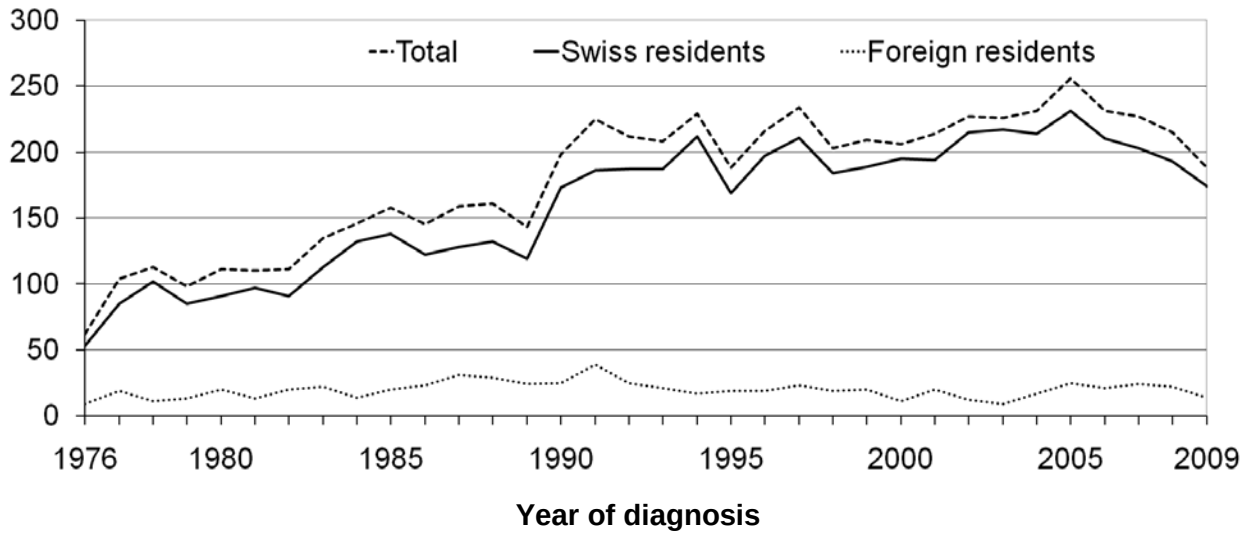


Table 2 – Number of cases registered, by period of diagnosis (5-year intervals)

Including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2009 (N=6099)

Period of diagnosis	All cases	Swiss residents	
		n	mean
1976-1979*	377	325	81.3
1980-1984	613	524	104.8
1985-1989	766	639	127.8
1990-1994	1072	945	189.0
1995-1999	1050	950	190.0
2000-2004	1104	1035	207.0
2005-2009	1117	1011	202.2
TOTAL	**6099**	**5429**	**159.7**

* This period includes 4 years only

3.2 Cases aged 0-14 years at diagnosis and resident in Switzerland (N=5000)

This chapter includes cases aged 0-14 years and resident in Switzerland at the time of diagnosis, and with a diagnostic code according to ICCC-3 or a Langerhans cell histiocytosis. This is the age group usually covered in international publications; therefore the tables and figures can be compared directly to data from other countries. By 31st December 2009, the SCCR contained data from 5000 children who were both aged 0-14 years and resident in Switzerland at the time of diagnosis.

Age at diagnosis

Almost half of cases (46%) had been diagnosed between the ages of 0-4 years: 10% during infancy (0-1 year old) and 36% in the age group 1-4 years old (**Figure 2**). Incidence is lowest at age 9-10 years, and then increases again (**Figure 3**). As seen in other childhood cancer registries more boys than girls were diagnosed with cancer.

Figure 2 – Age at diagnosis

Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2009 (N=5000)

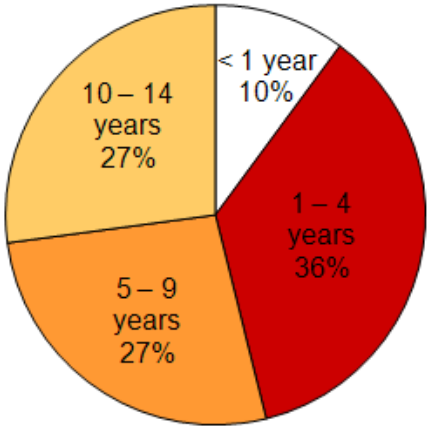
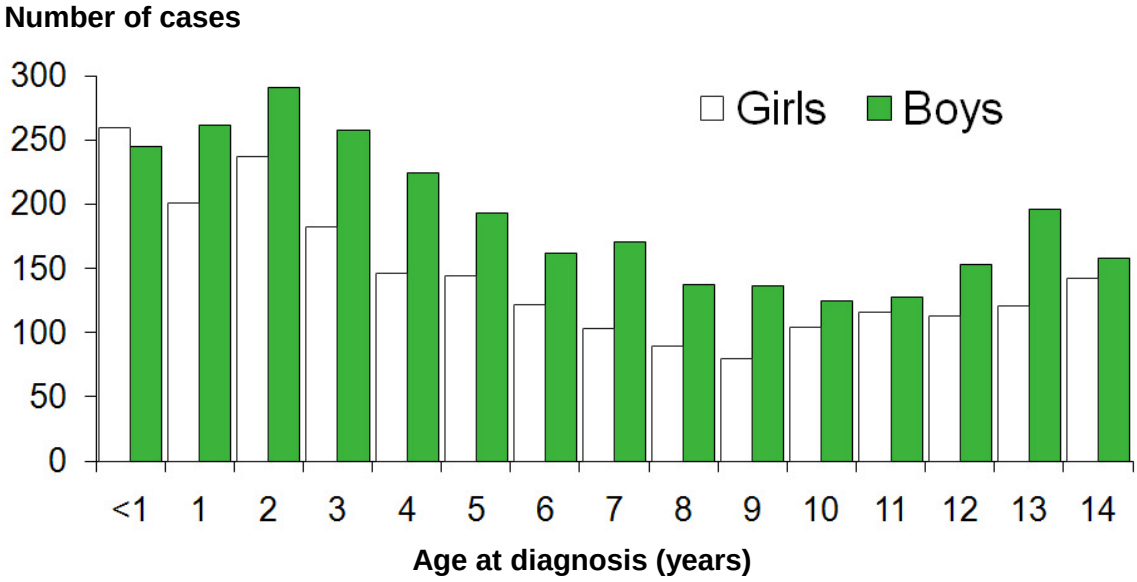


Figure 3 – Age at diagnosis, by sex

Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2009 (N=5000)



Diagnostic groups

Table 3 – Diagnostic groups according to ICCC-3

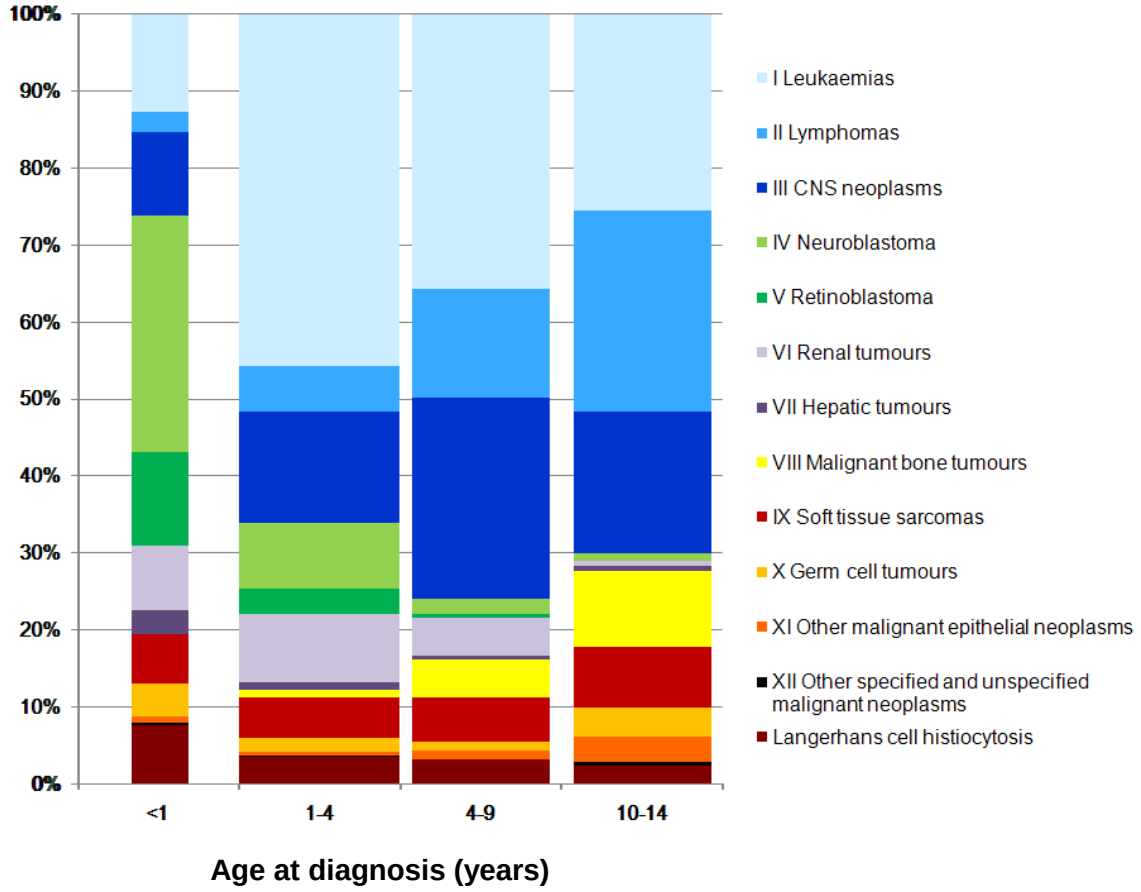
Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2009 (N=5000)

Diagnosis		Total number		Age at diagnosis (years)							
				<1		1-4		5-9		10-14	
		n	%	n	%	n	%	n	%	n	%
I	Leukaemias, myeloproliferative diseases and myelodysplastic diseases	1711	34.2	64	12.7	824	45.8	477	35.7	346	25.5
II	Lymphomas and reticuloendothelial neoplasms	663	13.3	13	2.6	105	5.8	190	14.2	355	26.2
III	Central nervous system neoplasms	916	18.3	55	10.9	263	14.6	349	26.1	249	18.4
IV	Neuroblastoma and other peripheral nervous cell tumours	347	6.9	155	30.7	153	8.5	26	1.9	13	1.0
V	Retinoblastoma	130	2.6	62	12.3	60	3.3	7	0.5	1	0.1
VI	Renal tumours	276	5.5	42	8.3	159	8.8	66	4.9	9	0.7
VII	Hepatic tumours	49	1.0	16	3.2	18	1.0	6	0.4	9	0.7
VIII	Malignant bone tumours	215	4.3	0	0.0	17	0.9	66	4.9	132	9.7
IX	Soft tissue and other extraosseous sarcomas	310	6.2	32	6.3	94	5.2	77	5.8	107	7.9
X	Germ cell tumours, trophoblastic tumours and neoplasms of gonads	126	2.5	22	4.4	34	1.9	17	1.3	53	3.9
XI	Other malignant epithelial neoplasms and malignant melanomas	70	1.4	4	0.8	7	0.4	15	1.1	44	3.2
XII	Other specified and unspecified malignant neoplasms	13	0.3	2	0.4	4	0.2	0	0.0	7	0.5
	Langerhans cell histiocytosis	174	3.5	38	7.5	63	3.5	42	3.1	31	2.3
	TOTAL	**5000**	**100.0**	**505**	**100.0**	**1801**	**100.0**	**1338**	**100.0**	**1356**	**100.0**

Figure 4 – Diagnostic groups according to ICCC-3 and age at diagnosis (years)

Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2009 (N=5000)

The widths of the columns are proportional to the number of cases.



Follow-up information

The SCCR has several ways to collect follow-up information for registered cases:

- **Short-term clinical follow-up** is done by paediatric haematology-oncology centres. Clinical follow-up usually ends 5-10 years after diagnosis when the patient is officially discharged or referred to an adult oncology centre, or if the patient dies.
- **Long-term epidemiological follow-up** is done via three complementary approaches:
  - postal questionnaires to survivors in the Swiss Childhood Cancer Survivor Study (SCCSS, chapter 4, project 4)
  - systematic assessment of vital status by contacting community registries and linkage with the Swiss mortality statistics to retrieve causes of death (chapter 5)
  - detection of secondary cancers by regular comparison with cantonal (=regional) cancer registries in Switzerland

Table 4 summarises the follow-up status of all cases aged 0-14 years at diagnosis. In total 1232 of the 5000 children (25%) died. **Short-term clinical follow-up data** is available for 1833 (37%) children for the period 2005-2009. For 428 (9%) and 600 (12%) children, the last clinical follow-up report is older, from 2000-2004 or before 2000 respectively. These are mainly cases diagnosed before 1995. **Long-term epidemiological follow-up data** are available for the large majority of cases. Only 285 (5.7%) of cases are lost to follow-up, mostly because they moved abroad. For the other 3483 survivors, their vital status and current address have been updated during 2007-10, and for 1457 of these we also have morbidity data from the SCCSS questionnaire survey from 2007-10.

Table 4 – Follow-up information of cases in the SCCR databases

Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976-2009 (N=5000)

	Number of cases	%
Short-term clinical follow-up		
Died	1232	24.6
Last clinical follow-up since Jan 2005	1833	36.7
Last clinical follow-up 2000-2004	428	8.6
Last clinical follow-up before 2000	600	12.0
No clinical follow-up	907	18.1
TOTAL	5000	100.0
Long-term epidemiological follow-up		
Update of vital status, current address and current health via questionnaire survey (2007-2010)*	1457	29.1
Update of vital status and current address via community registries only (2007-2010)	2026	40.5
Died, and causes of death retrieved from mortality statistics	1232	24.6
Lost to follow-up (address and vital status unknown)	285	5.7
TOTAL	5000	100.0

* only cases diagnosed before 01.05.2003 were eligible for the SCCSS questionnaire survey

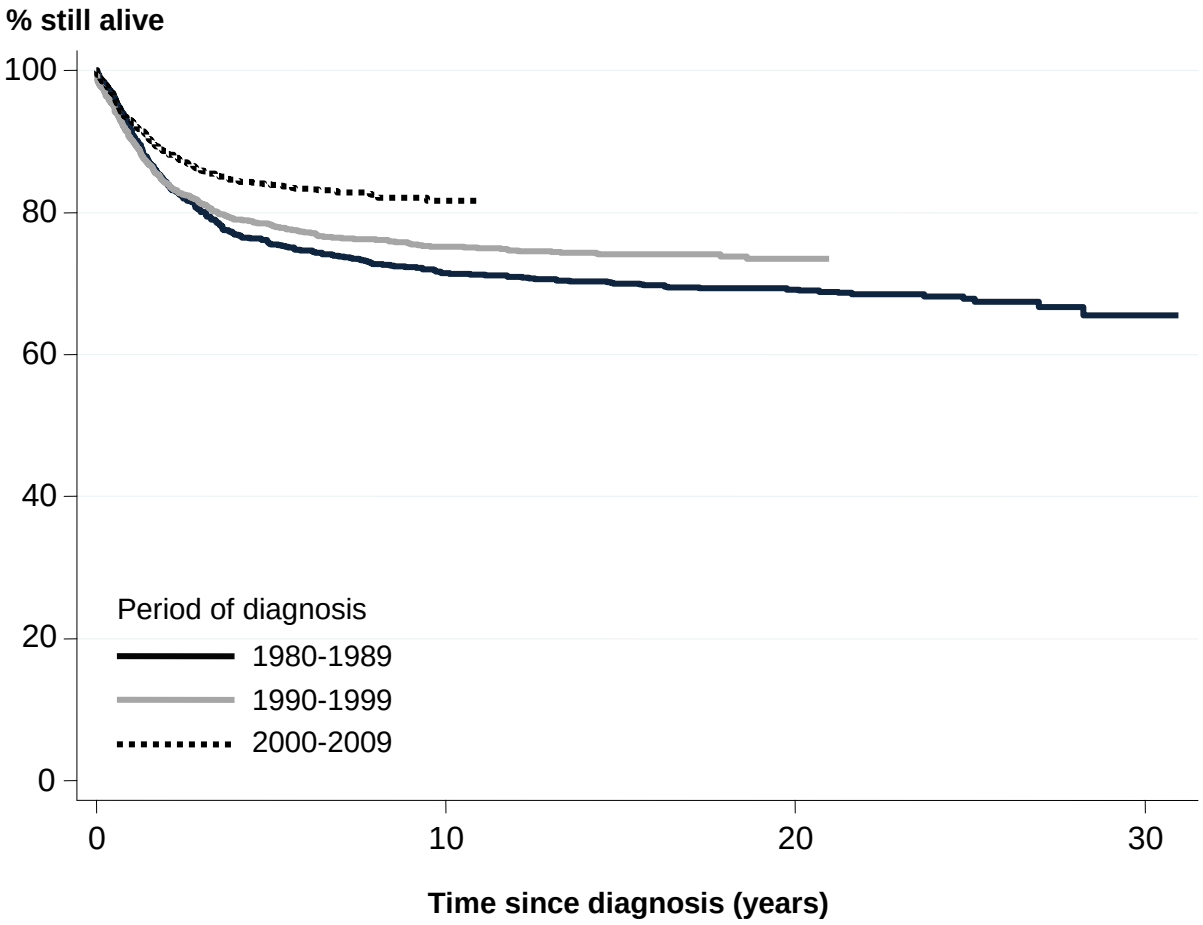
Survival

Data on the survival of cases registered in the SCCR are presented for the first time in this report.

Figure 5 shows an actuarial curve presenting overall survival up to 30 years after diagnosis for cases diagnosed between 1980-2009 (N=4694) grouped in three ten year periods. A total of 1076 children (23%) have died. Ten-year survival increased from 68% in children diagnosed between 1980-1989, to 75% in children diagnosed between 1990 and 1999 and reached over 82% in children diagnosed in the last ten years.

Figure 5 – Survival of cases in the SCCR, by period of diagnosis

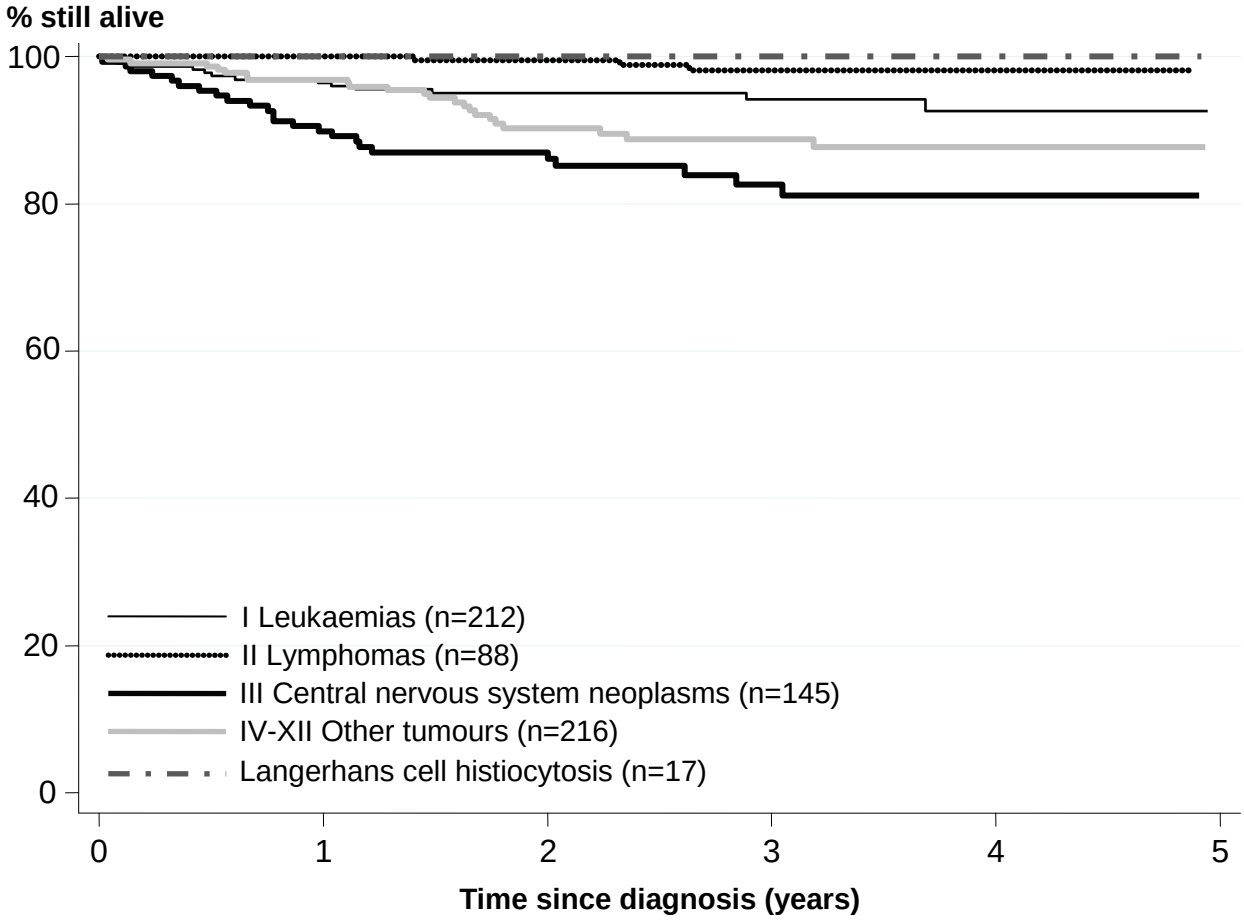
Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1980-2009 (adjusted results for sex, age at diagnosis and ICCC-3 groups, N=4694)



Survival varies widely between diagnostic groups. **Figure 6** presents survival for five diagnostic categories, in cases diagnosed from 2006-2009 (N=678). Five-year survival was above 80% in all diagnostic categories: it reached 93% for children diagnosed with leukaemias; 98% for those with lymphomas; 81% for children with central nervous system neoplasms; 88% for those with other tumours (including neuroblastoma, retinoblastoma, renal tumours, hepatic tumours, malignant bone tumours, soft tissue sarcomas, germ cell tumours, other specified and unspecified malignant neoplasms) and 100% in children diagnosed with Langerhans cell histiocytosis.

Figure 6 – Survival of cases by diagnostic groups according to ICCC-3

Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 2006-2009 (adjusted results, N=678)



Diagnosis (ICCC-3) for cases registered and resident in Switzerland

Table 5 reports diagnosis according to ICCC-3 for all cases registered in the SCCR during the past 10 years (2000-2009).

Overall more boys than girls were diagnosed with cancer. This was true for most types of tumours with the exception of neuroblastoma, germ cell tumours and other malignant epithelial neoplasms.

The age-standardised incidence of any childhood cancer (not including Langerhans cell histiocytosis) was 14.8 cases per 100,000 person-years. Incidence was highest among children aged less than 1 year with 24.5 cases per 100,000 person-years and lowest in 5-9 year olds with 11.7 cases per 100,000 person-years (**Figure 7** showing crude incidence rates and **Figure 8** showing age- and sex-specific incidence rates according to the European population for age-groups under 15 years[8]).

The relative frequency of the different diagnoses, sex ratio, mean age at diagnosis and age-standardised incidence are similar to results from Germany.[9]

8 J Waterhouse *et al* (eds). Cancer incidence in five continents. Lyon: International Agency for Research on Cancer, World Health Organization; 1976 (Vol. 3, p. 456).
9 Kaatsch P, Spix C. Annual report 2008: German Childhood Cancer Registry (GCCR). Mainz; 2009.

Table 5 – Number of registered cases in the SCCR, sex ratio, mean age at diagnosis and age-standardised incidence* (per 100,000 person-years), by diagnostic groups according to ICCC-3

Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 2000-2009 (N=1822)

		n	Relative frequency	Sex ratio (male: female)	Mean age	Incidence*
I	**Leukaemias, myeloproliferative diseases and myelodysplastic diseases**	**565**	**31.8**	**1.3**	**4.9**	**4.7**
	a. Lymphoid leukaemias	460	81.4	1.3	4.8	3.8
	b. Acute myeloid leukaemias	75	13.3	1.8	5.4	0.6
	c. Chronic myeloproliferative diseases	3	0.5	2.0	11.0	0.0
	d. Myelodysplastic syndrome and other myeloproliferative diseases	18	3.2	1.0	8.5	0.1
	e. Unspecified and other specified leukaemias	9	1.6	1.3	3.3	0.1
II	**Lymphomas and reticuloendothelial neoplasms**	**222**	**12.5**	**2.0**	**10.7**	**1.8**
	a. Hodgkin lymphomas	94	42.3	1.0	12.5	0.8
	b. Non-Hodgkin lymphomas (except Burkitt lymphoma)	79	35.6	3.2	9.1	0.7
	c. Burkitt lymphoma	42	18.9	6.0	7.2	0.3
	d. Miscellaneous lymphoreticular neoplasms	6	2.7	1.0	1.1	0.0
	e. Unspecified lymphomas	1	0.5	0.0	13.6	0.0
III	**CNS and miscellaneous intracranial and intraspinal neoplasms**	**419**	**23.6**	**1.2**	**6.9**	**3.5**
	a. Ependymomas and choroid plexus tumours	32	7.6	1.1	2.4	0.3
	b. Astrocytomas	162	38.7	1.3	7.1	1.3
	c. Intracranial and intraspinal embryonal tumours	97	23.2	1.6	5.4	0.8
	d. Other gliomas	45	10.7	0.8	5.9	0.4
	e. Other specified intracranial and intraspinal neoplasms	77	18.4	0.9	10.1	0.6
	f. Unspecified intracranial and intraspinal neoplasms	6	1.4	1.0	9.1	0.0
IV	**Neuroblastoma and other peripheral nervous cell tumours**	**119**	**6.7**	**0.9**	**1.0**	**1.0**
	a. Neuroblastoma and ganglioneuroblastoma	119	100.0	0.9	1.0	1.0
V	**Retinoblastoma**	**38**	**2.1**	**0.7**	**1.0**	**0.3**
VI	**Renal tumours**	**94**	**5.3**	**1.1**	**3.0**	**0.8**
	a. Nephroblastoma and other nonepithelial renal tumours	91	96.8	1.2	2.9	0.8
	b. Renal carcinomas	3	3.2	0.5	12.8	0.0

Table 5 – continued

		n	Relative frequency	Sex ratio (male: female)	Mean age	Incidence*
VII	**Hepatic tumours**	**21**	**1.2**	**4.3**	**1.7**	**0.2**
	a. Hepatoblastoma	18	85.7	5.0	1.5	0.1
	b. Hepatic carcinomas	3	14.3	2.0	13.9	0.0
VIII	**Malignant bone tumours**	**91**	**5.1**	**1.0**	**10.6**	**0.8**
	a. Osteosarcomas	44	48.4	0.8	10.9	0.3
	c. Ewing tumour and related sarcomas of bone	47	51.6	1.2	10.3	0.4
IX	**Soft tissue and other extra osseous sarcomas**	**119**	**6.7**	**1.3**	**7.9**	**1.0**
	a. Rhabdomyosarcomas	74	62.2	1.6	5.3	0.6
	b. Fibrosarcomas, peripheral nerve sheath tumours and other fibrous neoplasms	7	5.9	0.8	7.0	0.1
	d. Other specified soft tissue sarcomas	28	23.5	1.0	11.9	0.2
	e. Unspecified soft tissue sarcomas	10	8.4	1.0	7.3	0.1
X	**Germ cell tumours, trophoblastic tumours, and neoplasms of gonads**	**48**	**2.7**	**0.7**	**8.3**	**0.4**
	a. Intracranial and intraspinal germ cell tumours	8	16.7	3.0	9.5	0.1
	b. Malignant extracranial and extragonadal germ cell tumours	16	33.3	0.3	1.8	0.1
	c. Malignant gonadal germ cell tumours	23	47.9	0.6	12.0	0.2
	d. Gonadal carcinomas	1	2.1	0.0	13.9	0.0
XI	**Other malignant epithelial neoplasms and malignant melanomas**	**36**	**2.0**	**1.3**	**11.3**	**0.3**
	a. Adrenocortical carcinomas	1	2.8		2.0	0.0
	b. Thyroid carcinomas	12	33.3	1.0	12.3	0.1
	d. Malignant melanomas	15	41.7	0.9	8.6	0.1
	e. Skin carcinomas	2	5.6		7.2	0.0
	f. Other and unspecified carcinomas	6	16.7	2.0	12.0	0.0
XII	**Other specified and unspecified malignant neoplasms**	**3**	**0.2**	**0.5**	**12.9**	**0.0**
	a. Other specified malignant tumours	1	33.3		12.9	0.0
	b. Other unspecified malignant tumours	2	66.7	0.0	7.6	0.0
	Total (not including Langerhans cell histiocytosis)	**1'775**	**100.0**	**1.3**	**6.7**	**14.8**
	Langerhans cell histiocytosis	**47**	**2.6**	**1.1**	**4.4**	**0.4**
	Total (including Langerhans cell histiocytosis)	**1'822**	**100.0**	**1.3**	**6.7**	**15.1**

* Incidence: newly diagnosed cases in a one year time period per 100,000 persons

Figure 7 – Crude incidence rate (per 100,000 person-years) in Switzerland, by sex and year of diagnosis

Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 but not including Langerhans cell histiocytosis), years of diagnosis 1990-2009 (N=3466)

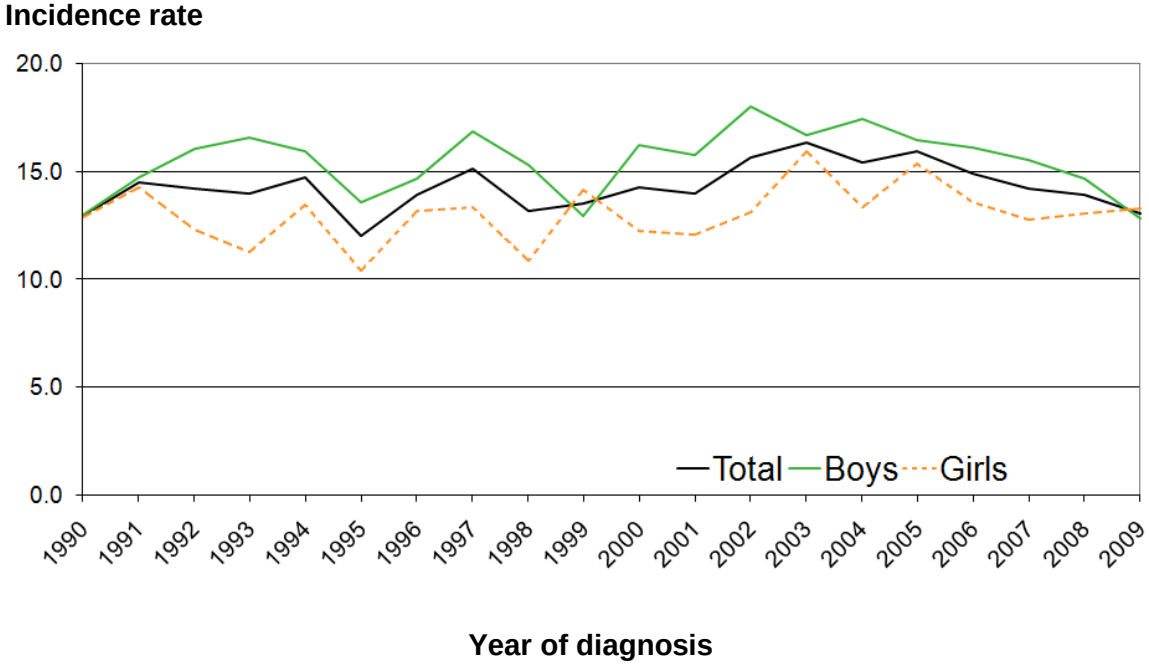
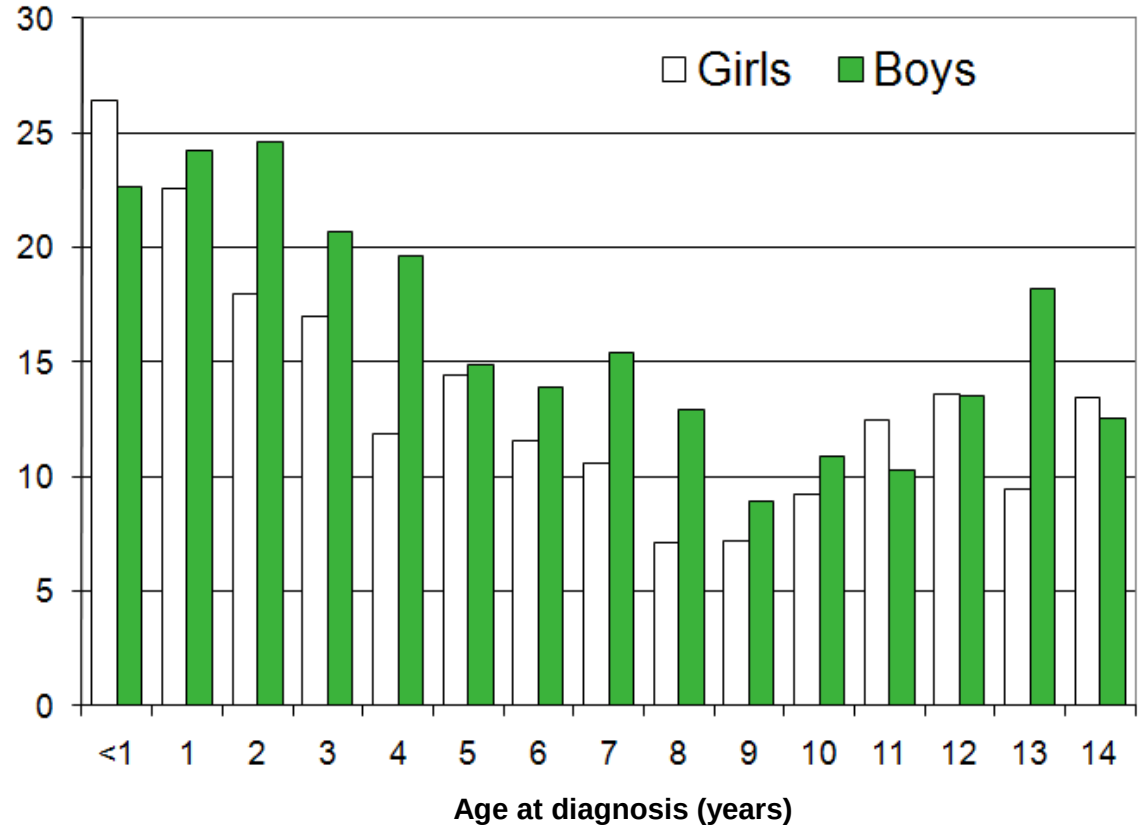


Figure 8 – Age- and sex-specific incidence rates (per 100,000 person-years) in Switzerland

Swiss residents, aged 0-14 years at diagnosis, all diagnoses (ICCC-3 but not including Langerhans cell histiocytosis), years of diagnosis 2000-2009 (N=1775)



3.3 Cases reported by the 9 centres of the Swiss Paediatric Oncology Group

Tables 6, 7 and **8** show the distribution of cases reported from the 9 SPOG centres for the periods 1976-1989, 1990-1999 and 2000-2009 respectively. **Tables 9** and **10** show the numbers reported from the different SPOG centres in the years 2008 and 2009 respectively.

These tables include all cases irrespective of age and place of residence (Swiss and foreign cases).

Cases reported for the years 1976-2009

A total of 1756 cases were registered in the SCCR in the years 1976-1989. During the first period (1976-1989), most cases were reported from the paediatric haematology-oncology centres of Bern (n=511, 29%), Zurich (n=293, 17%) and Lausanne (n=220, 13%). For 6 cases the treating institution is unknown (**Table 6**). During the second period (1990-1999), 56% of cases were reported from the centres of Bern (n=416, 20%), Zurich (n=388, 18%) and Lausanne (n=386, 18%; **Table 7**). During the third period (2000-2009), a total of 2221 cases were reported (Bern, n=350, 16%; Zurich, n=574, 26%; and Lausanne, n=410, 19%; **Table 8**). Most cases with retinoblastoma were reported by Lausanne (39%, 71% and 85% in the periods 1976-1989, 1990-1999 and 2000-2009, respectively) because they are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne.

Cases reported for the years 2008-2009

The 9 SPOG centres reported 215 newly diagnosed cases to the SCCR in 2008 and 186 in 2009 (**Tables 9** and **10**). The slight reduction in new cases in 2009 was mainly due to a lower number of leukaemias (63 in 2008 and 49 in 2009).

Table 6 – Number of children diagnosed* with cancer between 1976 and 1989, by participating paediatric oncology centre

Including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1976 -1989 (N=1756)
All cases irrespective of age and place of residency (Swiss and foreign cases) are included in this table.

	Diagnosis	Total		Aarau		Basel		Bern		Geneva		Lausanne		Locarno		Lucerne		St Gallen		Zurich		Unknown‡	
		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
I	Leukaemias	664	100	50	7.5	75	11.3	194	29.2	59	8.9	56	8.4	2	0.3	49	7.4	70	10.5	106	16.0	3	0.5
II	Lymphomas	284	100	21	7.4	29	10.2	79	27.8	19	6.7	37	13.0	1	0.4	16	5.6	28	9.9	53	18.7	1	0.4
III	Central nervous system neoplasms	200	100	12	6.0	15	7.5	83	41.5	15	7.5	23	11.5	1	0.5	1	0.5	21	10.5	29	14.5	0	0.0
IV	Neuroblastoma	131	100	5	3.8	11	8.4	26	19.8	14	10.7	21	16.0	0	0.0	8	6.1	11	8.4	34	26.0	1	0.8
V	Retinoblastoma†	62	100	0	0.0	3	4.8	12	19.4	11	17.7	24	38.7	1	1.6	1	1.6	6	9.7	4	6.5	0	0.0
VI	Renal tumours	97	100	4	4.1	11	11.3	23	23.7	6	6.2	10	10.3	0	0.0	14	14.4	8	8.2	21	21.6	0	0.0
VII	Hepatic tumours	11	100	0	0.0	1	9.1	4	36.4	2	18.2	1	9.1	0	0.0	0	0.0	0	0.0	3	27.3	0	0.0
VIII	Malignant bone tumours	87	100	4	4.6	11	12.6	28	32.2	8	9.2	18	20.7	0	0.0	4	4.6	7	8.0	6	6.9	1	1.1
IX	Soft tissue sarcomas	109	100	3	2.8	13	11.9	35	32.1	8	7.3	14	12.8	0	0.0	10	9.2	10	9.2	16	14.7	0	0.0
X	Germ cell tumours	43	100	3	7.0	1	2.3	12	27.9	5	11.6	7	16.3	1	2.3	1	2.3	3	7.0	10	23.3	0	0.0
XI	Other malignant epithelial neoplasms	14	100	0	0.0	0	0.0	5	35.7	4	28.6	3	21.4	0	0.0	0	0.0	1	7.1	1	7.1	0	0.0
XII	Other specified and unspecified malignant neoplasms	4	100	0	0.0	0	0.0	1	25.0	0	0.0	2	50.0	0	0.0	0	0.0	0	0.0	1	25.0	0	0.0
	Langerhans cell histiocytosis	50	100	2	4.0	6	12.0	9	18.0	3	6.0	4	8.0	0	0.0	4	8.0	13	26.0	9	18.0	0	0.0
	TOTAL	1'756	100	104	5.9	176	10.0	511	29.1	154	8.8	220	12.5	6	0.3	108	6.2	178	10.1	293	16.7	6	0.3

* Diagnosis coded according to ICCC-3 and Langerhans cell histiocytosis

† Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

‡ Treating institution unknown. This is usually the case for children indentified via pathology laboratories, cantonal cancer registries or mortality statistics

Table 7 – Number of children diagnosed* with cancer between 1990 and 1999, by participating paediatric oncology centre

Including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 1990-1999 (N=2122)
All cases irrespective of age and residency (Swiss and foreign cases) are included in this table.

	Diagnosis	Total		Aarau		Basel		Bern		Geneva		Lausanne		Locarno		Lucerne		St Gallen		Zurich		Unknown‡	
		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
I	Leukaemias	631	100	46	7.3	46	7.3	124	19.7	51	8.1	82	13.0	19	3.0	54	8.6	61	9.7	127	20.1	21	3.3
II	Lymphomas	256	100	17	6.6	24	9.4	42	16.4	25	9.8	41	16.0	12	4.7	18	7.0	15	5.9	48	18.8	14	5.5
III	Central nervous system neoplasms	398	100	22	5.5	28	7.0	105	26.4	33	8.3	49	12.3	12	3.0	9	2.3	26	6.5	78	19.6	36	9.0
IV	Neuroblastoma	135	100	3	2.2	17	12.6	20	14.8	13	9.6	27	20.0	1	0.7	10	7.4	10	7.4	27	20.0	7	5.2
V	Retinoblastoma†	140	100	0	0.0	6	4.3	5	3.6	7	5.0	100	71.4	1	0.7	7	5.0	4	2.9	6	4.3	4	2.9
VI	Renal tumours	109	100	2	1.8	11	10.1	23	21.1	11	10.1	13	11.9	0	0.0	5	4.6	11	10.1	30	27.5	3	2.8
VII	Hepatic tumours	24	100	0	0.0	3	12.5	7	29.2	0	0.0	4	16.7	1	4.2	0	0.0	1	4.2	8	33.3	0	0.0
VIII	Malignant bone tumours	116	100	2	1.7	20	17.2	28	24.1	19	16.4	17	14.7	3	2.6	4	3.4	6	5.2	11	9.5	6	5.2
IX	Soft tissue sarcomas	130	100	8	6.2	8	6.2	20	15.4	6	4.6	26	20.0	3	2.3	9	6.9	15	11.5	21	16.2	14	10.8
X	Germ cell tumours	62	100	4	6.5	8	12.9	11	17.7	5	8.1	9	14.5	1	1.6	1	1.6	3	4.8	16	25.8	4	6.5
XI	Other malignant epithelial neoplasms	28	100	2	7.1	3	10.7	6	21.4	1	3.6	3	10.7	2	7.1	1	3.6	0	0.0	2	7.1	8	28.6
XII	Other specified and unspecified malignant neoplasms	9	100	0	0.0	3	33.3	0	0.0	0	0.0	1	11.1	0	0.0	0	0.0	0	0.0	0	0.0	5	55.6
	Langerhans cell histiocytosis	84	100	3	3.6	9	10.7	25	29.8	2	2.4	14	16.7	3	3.6	5	6.0	9	10.7	14	16.7	0	0.0
	TOTAL	2122	100	109	5.1	186	8.8	416	19.6	173	8.2	386	18.2	58	2.7	123	5.8	161	7.6	388	18.3	122	5.7

* Diagnosis coded according to ICCC-3 and Langerhans cell histiocytosis

† Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

‡ Treating institution unknown. This is usually the case for children indentified via pathology laboratories, cantonal cancer registries or mortality statistics

Table 8 – Number of children diagnosed[*] with cancer between 2000 and 2009, by participating paediatric oncology centre

Including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), years of diagnosis 2000-2009 (N=2221)
All cases irrespective of age and place of residency (Swiss and foreign cases) are included in this table.

	Diagnosis	Total		Aarau		Basel		Bellinzona[§]		Bern		Geneva		Lausanne		Locarno		Lucerne		St Gallen		Zurich		Unknown[‡]	
		n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
I	Leukaemias	632	100	36	5.7	51	8.1	5	0.8	111	17.6	38	6.0	90	14.2	14	2.2	42	6.6	68	10.8	170	26.9	7	1.1
II	Lymphomas	291	100	22	7.6	17	5.8	3	1.0	50	17.2	17	5.8	45	15.5	5	1.7	34	11.7	30	10.3	60	20.6	8	2.7
III	Central nervous system neoplasms	524	100	21	4.0	28	5.3	4	0.8	91	17.4	33	6.3	89	17.0	10	1.9	19	3.6	34	6.5	172	32.8	23	4.4
IV	Neuroblastoma	127	100	7	5.5	9	7.1	0	0.0	19	15.0	8	6.3	25	19.7	0	0.0	9	7.1	10	7.9	40	31.5	0	0.0
V	Retinoblastoma[†]	91	100	1	1.1	3	3.3	0	0.0	3	3.3	0	0.0	77	84.6	0	0.0	2	2.2	1	1.1	3	3.3	1	1.1
VI	Renal tumours	99	100	9	9.1	6	6.1	1	1.0	17	17.2	9	9.1	11	11.1	4	4.0	6	6.1	7	7.1	29	29.3	0	0.0
VII	Hepatic tumours	24	100	4	16.7	0	0.0	0	0.0	4	16.7	3	12.5	2	8.3	1	4.2	0	0.0	4	16.7	5	20.8	1	4.2
VIII	Malignant bone tumours	125	100	5	4.0	22	17.6	0	0.0	16	12.8	12	9.6	27	21.6	2	1.6	1	0.8	12	9.6	26	20.8	2	1.6
IX	Soft tissue sarcomas	143	100	14	9.8	12	8.4	1	0.7	20	14.0	10	7.0	21	14.7	3	2.1	12	8.4	7	4.9	35	24.5	8	5.6
X	Germ cell tumours	61	100	9	14.8	2	3.3	0	0.0	4	6.6	6	9.8	11	18.0	1	1.6	5	8.2	7	11.5	12	19.7	4	6.6
XI	Other malignant epithelial neoplasms	50	100	2	4.0	4	8.0	0	0.0	6	12.0	1	2.0	3	6.0	0	0.0	6	12.0	7	14.0	10	20.0	11	22.0
XII	Other specified and unspecified malignant neoplasms	7	100	0	0.0	3	42.9	0	0.0	0	0.0	1	14.3	0	0.0	0	0.0	0	0.0	0	0.0	1	14.3	2	28.6
	Langerhans cell histiocytosis	47	100	5	10.6	4	8.5	0	0.0	9	19.1	1	2.1	9	19.1	1	2.1	1	2.1	6	12.8	11	23.4	0	0.0
	TOTAL	2221	100	135	6.1	161	7.2	14	0.6	350	15.8	139	6.3	410	18.5	41	1.8	137	6.2	193	8.7	574	25.8	67	3.0

* Diagnosis coded according to ICCC-3 and Langerhans cell histiocytosis

† Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

‡ Treating institution unknown. This is usually the case for children indentified via pathology laboratories, cantonal cancer registries or mortality statistics

§ Since 2008 cases of Ticino are treated in Bellinzona

Table 9 – Number of children diagnosed[*] with cancer in 2008, by participating paediatric oncology centre

Including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), new cases diagnosed in 2008 (N=215)
All cases irrespective of age and place of residence (Swiss and foreign cases) are included in this table.

	Diagnosis	Total	Aarau	Basel	Bellinzona	Bern	Geneva	Lausanne	Lucerne	St Gallen	Zurich	Unknown[‡]
I	Leukaemias	63	2	6	1	11	2	13	5	7	16	0
II	Lymphomas	29	4	1	2	3	2	3	3	5	5	1
III	Central nervous system neoplasms	43	1	3	2	7	2	8	1	4	14	1
IV	Neuroblastoma	20	0	0	0	4	2	8	0	1	5	0
V	Retinoblastoma[†]	7	0	0	0	0	0	7	0	0	0	0
VI	Renal tumours	8	1	0	1	2	0	0	1	0	3	0
VII	Hepatic tumours	1	0	0	0	0	0	0	0	1	0	0
VIII	Malignant bone tumours	15	0	2	0	3	1	2	0	4	3	0
IX	Soft tissue sarcomas	13	3	0	0	1	0	3	1	1	4	0
X	Germ cell tumours	7	2	0	0	0	1	1	0	1	2	0
XI	Other malignant epithelial neoplasms	5	0	1	0	1	0	0	0	0	1	2
XII	Other specified and unspecified malignant neoplasms	0	0	0	0	0	0	0	0	0	0	0
	Langerhans cell histiocytosis	4	0	0	0	1	0	1	0	0	2	0
	TOTAL	215	13	13	6	33	10	46	11	24	55	4

* Diagnosis coded according to ICCC-3 and Langerhans cell histiocytosis

† Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

‡ Treating institution unknown. This is usually the case for children indentified via pathology laboratories, cantonal cancer registries or mortality statistics

Table 10 – Number of children diagnosed* with cancer in 2009, by participating paediatric oncology centre

Including all age groups, all diagnoses (ICCC-3 or Langerhans cell histiocytosis), new cases diagnosed in 2009 (N=186)
All cases irrespective of age and place of residence (Swiss and foreign cases) are included in this table.

	Diagnosis	Total	Aarau	Basel	Bellinzona	Bern	Geneva	Lausanne	Lucerne	St. Gallen	Zurich
I	Leukaemias	49	4	3	4	5	2	7	5	3	16
II	Lymphomas	25	1	1	0	2	0	4	3	3	11
III	Central nervous system neoplasms	42	1	2	2	5	3	7	7	1	14
IV	Neuroblastoma	16	3	1	0	1	1	2	1	1	6
V	Retinoblastoma†	7	1	1	0	0	0	5	0	0	0
VI	Renal tumours	10	0	1	0	2	0	1	1	0	5
VII	Hepatic tumours	4	0	0	0	2	1	0	0	0	1
VIII	Malignant bone tumours	8	0	1	0	0	0	3	0	0	4
IX	Soft tissue sarcomas	15	2	1	1	2	0	3	1	0	5
X	Germ cell tumours	4	0	0	0	0	0	1	0	0	3
XI	Other malignant epithelial neoplasms	4	0	0	0	0	0	0	2	1	1
XII	Other specified and unspecified malignant neoplasms	0	0	0	0	0	0	0	0	0	0
	Langerhans cell histiocytosis	2	0	1	0	0	0	0	0	0	1
	TOTAL	186	12	12	7	19	7	33	20	9	67

* Diagnosis coded according to ICCC-3 and Langerhans cell histiocytosis

† Most cases with retinoblastoma are treated at the specialised Jules Gonin Eye Hospital at the University Hospital in Lausanne

4 Current research projects with data from the SCCR

The section on current research projects at the SCCR includes two chapters.

Chapter 4.1 lists studies conducted in one or several centres of the Swiss Paediatric Oncology Group (SPOG), where the SCCR provided data or performed the statistical analyses.

Chapter 4.2 describes recent or current research projects, which are conducted within the Child and Adolescent Health group at the Institute of Social and Preventive Medicine (ISPM), University of Bern.

We thank the supporters, listed in **Table 12** for their generous contributions towards the research projects.

4.1 Collaboration in research projects of the Swiss Paediatric Oncology Group

The overview describes projects initiated and led by SPOG members or where SPOG members are participating (single centre and multi centre projects, MD theses and PhD theses). The SCCR contributed by providing data from the SCCR database or by participating in the data analysis and interpretation.

Table 11 includes a list of these projects since 2007, with related publications.

4.2 Research projects conducted at the SCCR

This section relates to research projects initiated and conducted at the SCCR (located at the ISPM Bern), mainly using data from the SCCR, often in combination with additionally collected data (questionnaires) and sometimes using comparison data from other national datasets (such as the Swiss National Cohort or the Swiss Health Surveys).

Table 12 gives an overview of all recent and ongoing research projects conducted at the SCCR between 2005 and 2010. They are described in more detail in the remainder of chapter 4. Additional information is available from the references and from the investigators.

Table 11 – Collaboration in projects / studies conducted by the Swiss Paediatric Oncology Group since 2007

Title	Investigator	Population	Data extracted	Date of data extraction	Publications
Primitive neuroectodermal tumour (PNET), Medulloblastoma and Trisomy 21, update 2010	N. von der Weid, Lausanne	All cases with PNET, Medulloblastoma and prior relevant diseases (Trisomy 21)	Diagnosis and prior relevant diseases	Dec 10	Publication in preparation (international collaboration)
Malnutrition in childhood cancer cases, MSc thesis	K. Zimmermann, Bern	All cases from Bern, Basel, and Zurich, diagnosed between 2004-2006 treated with chemo- or radiotherapy	Institution, date of birth, sex, diagnosis, date of diagnosis, state of tumour, protocol, nationality	Feb 10	Master thesis of Karin Zimmermann, MSc Health care science, March 2010 Publication in preparation
Epidemiological study about neurocognitive late effects in children with tumour or leukaemia	K. Leibundgut, Bern	All cases diagnosed between 2004-2008, with ICCC-3 code or Histiocytosis	ICCC-3, age at diagnosis, year of diagnosis. Calculation of prevalence	Dec 09	Feasibility study finished, grant application in preparation
Current address research for cases from cerebral tumour database Zurich	M. Grotzer, Zurich	Cases with cerebral tumour	Current addresses	Mar 09	Ongoing project
Annual Report	N. von der Weid, Lausanne	Cases with diagnosis date between 01.11.07–31.10.08	Diagnosis, year of diagnosis, year of relapse	Feb 09	Annual report 2009 SPOG
Primitive neuroectodermal tumour (PNET), Medulloblastoma and Trisomy 21	N. von der Weid, Lausanne	All cases with PNET, Medulloblastoma and prior relevant diseases (Trisomy 21)	Diagnosis and prior relevant diseases	Nov 08	Publication in preparation (international collaboration)

Table 11 - continued

Title	Investigator	Population	Data extracted	Date of data extraction	Publications
Annual Report	N. von der Weid, Lausanne	Cases with diagnosis date between 01.11.06–31.10.07	Diagnosis, year of diagnosis, year of relapse	Feb 08	Annual report 2008 SPOG
Wilms tumour, Soft tissue sarcoma (STS) and autologous bone marrow transplantation (BMT)	N. von der Weid, Lausanne	All cases with Wilms tumour or STS who had autologous bone marrow transplantation	Diagnosis, year of diagnosis, autologous BMT	May 07	Retrospective request of the European Group for Blood and Marrow Transplantation (EBMT)
Childhood acute myeloid leukaemias (AML): clinical significance of cytogenetic events at presentation and relapse	D. Betts, Zurich	All cases with AML registered in the SCCR	All information on case, tumour and therapy levels. Calculation of survival.	Feb 07	Betts DR et al. European Journal of Haematology 2007 [10]
Craniopharyngeoma cases in Bern	M. Janner, Bern	All cases with a Craniopharyngeoma from Bern	Names, dates of birth and diagnosis, sex	Jan 07	Presentation at an internal meeting, University Children's Hospital, Bern

For earlier collaborations (before 2007) please refer to the previous Annual Report 2007/2008

10 Betts DR. *et al*. The prognostic significance of cytogenetic aberrations in childhood acute myeloid leukaemia. A study of the Swiss Paediatric Oncology Group (SPOG). European Journal of Haematology 2007; 78:468-76.

Table 12 – Research projects conducted at the SCCR since 2005

No	Project name	Funding	Primary investigator	Study Type	Study period
1	Childhood Cancer and Nuclear Power Plants in Switzerland - CANUPIS	Federal Office of Public Health (FOPH) Swiss Cancer League	Kuehni CE	Cohort study	09.2008-12.2010
2	Childhood cancer and vicinity of residence to petrol stations and major roads: a census-based nationwide cohort study	Federal Office of Public Health (FOPH)	Feller M Kuehni CE	Cohort study	06.2010-11.2012
3	Developing a radon exposure model to predict domestic radon exposure for Swiss children	Swiss National Science Foundation	Röösli M	Cohort study	01.2011-12.2013
4	Swiss Childhood Cancer Survivor Study (SCCSS)	Oncosuisse	von der Weid NX Kuehni CE	Cohort study	01.2006-08.2010
5	Follow-up care after childhood and young adult cancer (CCFU)	Swiss National Science Foundation	Michel G	Cohort study	08.2009-07.2012
6	Risk of cancer and long-term mortality in children treated with Growth Hormone: Swiss participation in the EU FP7 project “SAGhE”	EU FP7 Oncosuisse	Mullis P Kuehni CE	Cohort study	01.2010-08.2012
7	Childhood leukaemia and lymphoma: are incidence and survival in Switzerland associated with socio-economic status?	Oncosuisse	Zwahlen M	Case-control study / Cohort study	08.2007-07.2009
8	An international case-control study on brain tumours in children and adolescents - CEFALO	Swiss Research Foundation on Mobile Communication Federal Office of Public Health (FOPH) Swiss National Science Foundation (Pro Doc Grant)	Röösli M	Case-control study	10.2005-12.2008

Project 1 – Childhood Cancer and Nuclear Power Plants in Switzerland - CANUPIS

This study addresses the question if residence in the proximity of a nuclear power plant (NPP) is associated with an increased risk of childhood cancer, and whether this can be explained by confounding, particularly by other area-based risk factors for childhood cancer which might cluster around nuclear power plants. Details are available from the CANUPIS-Homepage: www.canupis.ch.

Background: Since the reporting of a cluster of leukaemia cases around Sellafield in 1984, numerous studies have assessed the risk of childhood cancer and residence in the proximity of nuclear power plants (NPPs). These studies showed heterogeneous results, many with weak positive associations. An explanation for this excess is lacking. Emissions from NPPs during normal operation are low in comparison to the annual background exposure and dose-response studies do not support a causal association. A recent case-control study from Germany, showing a small but statistically significant increase in the risk of cancer, particularly leukaemia, in children aged less than five years and living near NPPs refuelled the public discussion about this potential hazard. The study, as many others, had methodological problems limiting the interpretability of the results, including i) a potential selection bias because of differential response rates of municipalities; ii) possible bias due to the selection of controls by local clerks; iii) lack of adjustment for potential confounding factors such as electric power lines, major roads, socio-economic status, and other factors; and iv) analysis of residency only at the time of cancer diagnosis (because of the known latency in the development of malignant diseases, the place of residence prior to the diagnosis is of great interest).

Objectives: To investigate whether living near a NPP increases the risk of childhood cancer in general, and childhood leukaemia in particular.

Methods: This is a census-based cohort study with national coverage. Selection bias is minimized by using geo-coded addresses for each child, adjusting for important potential confounders, and inclusion of residential history back to the date of birth. The study uses the Swiss National Cohort (SNC), a long-term, census-based, multipurpose cohort and research platform including all Swiss inhabitants (6.8 million people) to estimate person-years at risk. Cases are identified via the Swiss Childhood Cancer Registry (SCCR). Included are all cases born between January 1985 and December 2007, aged less than16 years at diagnosis and resident in Switzerland. Our main exposure is proximity to nuclear sites modelled as four categories (the inner 5 km zone, 5-10 km, 10-15 km and more than 15 km). The following confounders are included: distance to major roads, electric power lines and broadcast transmitters, natural ionising radiation, area statistics (e.g. pesticides from agriculture or golf courses), pollutants from industry, degree of urbanisation, socio-economic status (using the Sotomo-Index[11]) and average number of children per family at communal level.

Rational and significance: This study will add importantly to the current evidence base on the risk of childhood cancer and residence in the proximity of nuclear sites. It will overcome important methodological problems of previous studies. Given the fact that additional nuclear sites are currently planned in Switzerland, the topic is of high public health and policy relevance.

11 Hermann M, Heye C, Leuthold H. *Soziokulturelle Unterschiede in der Schweiz - Vier Indizes zu räumlichen Disparitäten, 1990–2000* In: Bundesamt für Statistik (BFS)s pp. 70. Neuchâtel: Bundesamt für Statistik, 2005, http://sotomo.geo.unizh.ch/papers/soziokult.pdf.

Study Team

Applicants: Kuehni CE. Institute of Social and Preventive Medicine, University of Bern; Röösli M. Swiss Tropical and Public Health Institute, University of Basel; Von der Weid NX. Paediatric Oncology, CHUV Lausanne; Hengartner H. Ostschweizer Kinderspital, St. Gallen; Niggli F. University Children's Hospital, Zurich; Egger M. Institute of Social and Preventive Medicine, University of Bern.
Project team: Feller M, Kuehni CE, Spycher B, Zwahlen M, Gueler A, Institute of Social and Preventive Medicine, University of Bern.

Funding: Federal Office of Public Health (FOPH); Swiss Cancer League

Contact: Claudia Kuehni (kuehni@ispm.unibe.ch)

Publications: Expected for 2011

Project 2 – Childhood cancer and vicinity of residence to petrol stations and major roads: a census-based nationwide cohort study

Background: The aetiology of childhood cancer is not well understood and research on possible causal agents is required. Benzene is a traffic-related air pollutant, which is known to be haematotoxic and an established carcinogen in humans. The association with acute myeloid leukaemia is well documented in adults, but data on children are scarce.

Objective: To examine whether residence in the proximity of petrol stations, motor vehicle service stations or major roads as well as parental profession-related exposure to benzene is associated with an increased risk of any type of cancer and of leukaemia in Swiss children and adolescents aged 0-19 years.

Methods: The study will include all children born between January 1985 and December 2008, aged <20 years and resident in Switzerland. Analyses will be based on information obtained from the SCCR, the Swiss National Birth Registry (NBR) and the Swiss National Cohort (SNC), a long-term, census-based cohort that includes all Swiss inhabitants (6.8 million people). All addresses will be geo-coded to assess proximity to petrol stations, motor vehicle stations and major roads. Data sources are the census of business and the Teleatlas database.
From January 1985 to December 2008 about 4500 children and adolescents aged <20 years were diagnosed with cancer in Switzerland, including 1300 with acute leukaemia. As the main exposure we will calculate proximity to petrol stations, motor vehicle service stations or major roads. Additionally we will analyse if children with one or both parents working in benzene-exposed occupations are at higher risk for childhood cancer than children whose parents do not work in benzene-exposed occupations. Information on occupation will be extracted from the 1990 and 2000 censuses. The data will be analysed using Poisson regression models, adjusting for a range of potential confounders, including the socio-economic status of parents, maternal and paternal age at birth, birth weight and length, birth order, and the number of siblings.

Rational and Significance: Traffic-related pollution and its effects on health are a major public health issue because a substantial proportion of the population is exposed. This unique, large-scale study will make an important contribution to the evidence on a possible association between traffic-related air pollution and childhood cancer.

Study Team

Applicants: Feller M, Spoerri A. Institute of Social and Preventive Medicine, University of Bern; Von der Weid NX. Paediatric Oncology, CHUV Lausanne; Zwahlen M, Egger M, Kuehni CE. Institute of Social and Preventive Medicine, University of Bern;
Project team: Mueller M, Spoerri A, Zwahlen M, Gueler A, Kuehni CE. Institute of Social and Preventive Medicine, University of Bern.

Funding: Federal Office of Public Health (FOPH)

Contact: Claudia Kuehni (kuehni@ispm.unibe.ch)

Publications: Expected for 2012

Project 3 – Developing a radon exposure model to predict domestic radon exposure for Swiss children

Background: Although cancer in children under 15 years of age is rare, it was the second most common cause of death in children in the United States in 2005 and the third most common cause of death in children in the European Union in 2000 and also accounts for a high burden of disability because of late effects in survivors. There is evidence that radon exposure is associated with lung cancers in adults, but less is known with respect to the association with childhood cancers. Studies published on this issue so far are ecological studies that do not control for possible confounders or case-control studies with inconsistent results and possible recall and selection bias.

Objectives: To develop a radon exposure model and to predict domestic radon exposure for children in Switzerland. To investigate if an elevated indoor radon concentration increases the risk of childhood cancer in general, and of acute lymphoblastic leukaemia (ALL) in particular.

Methods: A prospective census-based cohort design will be used to investigate the potential association between radon exposure and childhood cancer. All children aged between 0 and 15 years, born before 4th December 2000 (date of census) and resident in Switzerland will be included in the cohort. Follow-up period will last until death, emigration or 31st December 2007. The SCCR will be used to identify eligible cases. In total, roughly 1000 childhood cancer cases, with approximately 250 ALL cases will be included. The Swiss National Cohort (SNC) will provide the place of residency on the date of census for all children of the cohort, mortality and emigration data for the calculation of follow-up time, and information about potential confounding factors such as socio-economic status or number of children in the household. The CANUPIS study (Childhood cancer and nuclear power plants in Switzerland) will provide residential history for all cancer cases. In order to assess individual exposure to radon at the place of residency, a model for domestic radon exposure will be developed using the radon data base of the Swiss Federal Office of Public Health and geographically referenced information (e.g. building register, geology). The radon database consists of indoor measurements for about 100,000 buildings in Switzerland. The prediction model will be validated with independent indoor radon measurements. Thereby, the aim is to use 20% of data from each canton for the model validation. Exposure to spatially variable potential confounders such as power lines or distance to streets will be calculated using geographic information systems (GIS). The data will be analyzed using established statistical methods for cohort studies, primarily Cox regression models adjusted for potential confounders.

Rationale and significance: This is a census-based cohort study with national coverage. Important potential confounders will be adjusted for and selection bias will be minimized because no direct contact with study participants is necessary. Thus, this study will be able to overcome major methodological problems of most previous studies on that topic and add significant insight to the open issue whether low dose ionizing radiation is associated with childhood cancer. The study will also provide novel information relating to the exposure of the Swiss population to radon by combining available measurements with modelling. Radon represents a preventable exposure. It is estimated to contribute to roughly half of the average annual ionizing radiation dose in Switzerland. Thus, the topic is of high public health relevance if radon is associated with childhood cancer.

Study Team

Applicants: Röösli M. Swiss Tropical and Public Health Institute Basel; Kuehni CE. Institute of Social and Preventive Medicine, University of Bern; Huss A. Institute for Risk Assessment Sciences, Utrecht University, The Netherlands
Project team: Hauri D, Röösli M. Swiss Tropical and Public Health Institute Basel; Kuehni CE. Institute of Social and Preventive Medicine, University of Bern; Zimmermann F. University Hospital Basel

Funding: Swiss National Foundation (SNF)

Contact: Martin Röösli (martin.roosli@unibas.ch)

Publications: Expected for 2011-2013

Project 4 – Swiss Childhood Cancer Survivor Study (SCCSS)

This is a survey of all long-term survivors (≥5 years after diagnosis) of childhood cancer in Switzerland, to assess the somatic and psychosocial late effects, health behaviours and health-related quality of life.

Background: Thanks to therapeutic improvements in the past decades, survival rates in childhood cancer now exceed 80%, leading to a growing population of long-term survivors. However, cancer and cancer treatments have been associated with adverse late effects. Therefore, the health and quality of life of survivors are a matter of increasing concern. In Switzerland and elsewhere, comprehensive data on the burden of late effects of childhood cancer and its risk factors, and data on use of follow-up care in long-term survivors are scarce.

Objectives: This project investigates the long-term outcome of former childhood cancer cases who were diagnosed with cancer before the age of 16 and who survived for more than 5 years. It studies the incidence and spectrum of various somatic and psycho-social outcomes (late mortality, secondary malignancies, endocrine disorders, infertility, cardiovascular events, psychological distress, educational achievement etc.) and health related quality of life (HRQoL), and their association with a number of risk factors assessed prospectively at the time of diagnosis (tumour, treatment modalities, demographic characteristics). In addition, the current practice of health-care provision and health behaviour in long-term survivors are investigated.

Methods: This is a prospective cohort study based on the population of children registered in the SCCR. Eligible for the study are 2738 individuals, who have been diagnosed before 1st May 2003 (i.e. at least 5 years prior to the beginning of the study), who are still alive, and who were Swiss residents at the time of diagnosis. The study population includes 1647 adults (≥ 20 years), 470 adolescents (15 – 20 years), and 621 children (5 – 15 years).
A detailed questionnaire is being sent to all participants, assessing demographic and socio-economic information, educational and professional achievements, current medical conditions and treatments, health-related quality of life (HRQoL), psychological well-being, health behaviour and healthcare provision. If consent is given, questionnaire data will be complemented with, and validated against general practitioner and hospital records. For comparing the results, the same questionnaire is being sent to all siblings of childhood cancer survivors who answered a questionnaire.

Rationale and significance: The existing database of the SCCR gives the rare opportunity for a nationwide study on long-term outcomes in survivors of childhood cancer. The project will increase the knowledge on the incidence of, and risk factors for late effects, and provide a summary of the current status of care in Switzerland. As many late effects can be prevented or cured if diagnosed early, this study will also contribute to improving the health of current and future survivors of childhood cancer.

Current status of the project: Up to August 2010, 1193 adult survivors had answered a questionnaire (78% of those contacted) as well as 312 adolescent survivors (69% of those contacted). The questionnaire for children was sent out in November 2010 and January 2011. Of the 749 siblings that could be traced and contacted, 451 (60%) answered the questionnaire. In 2011 the study population will be expanded and survivors diagnosed until 31.12.2005 will be included in the study. Some results from adult survivors have already been analysed and published (see below).

Study Team

Applicants: Von der Weid NX. Paediatric Oncology, CHUV Lausanne; Kuehni CE, Egger M, Zwahlen M. Institute of Social and Preventive Medicine, University of Bern; Probst-Hensch N. Department of Pathology / Department of Social and Preventive Medicine, University Hospital, Zurich; Niggli F. University Children's Hospital, Zurich.
Project team: Rüegg CS, Rebholz CE, Wengenroth L, Kuehni CE, Michel G, Koch J, Gianinazzi M. Institute of Social and Preventive Medicine, University of Bern; Von der Weid NX. Paediatric Oncology, CHUV Lausanne; Niggli F. University Children's Hospital, Zurich.

Funding: Swiss Cancer League (Grant No KLS-01605-10-2004 and KLS-2215-02-2008), Bernese Cancer League and Cancer League Zurich.

Contact: Corina Rüegg (crueegg@ispm.unibe.ch),
Claudia Kuehni (kuehni@ispm.unibe.ch)

Publications

Rebholz CE, von der Weid NX, Michel G, Niggli F, Kuehni CE. Follow-up care amongst long-term childhood cancer survivors: a report from the Swiss Childhood Cancer Survivor Study. *European Journal of Cancer 2011; 41:221-9.*

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Michel G, Rebholz CE, von der Weid NX, Bergstraesser E, Kuehni CE. Psychological distress in adult childhood cancer survivors: the Swiss Childhood Cancer Survivor Study. *Journal of Clinical Oncology 2010; 28:1740-7.*

Rueegg CS, Rebholz CE, Michel G, von der Weid NX, Zwahlen M, Grotzer M, Kuehni CE. Daily physical activity and sports in adult survivors of childhood cancer and healthy controls. *Submitted.*

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Kuehni CE, Strippoli MPF, Rueegg CS, Rebholz CE, Bergstraesser E, Grotzer M, von der Weid NX, Michel G. Educational achievement in Swiss childhood cancer survivors compared to the general population. *Submitted.*

Kuehni CE, Rueegg CS, Michel G, Rebholz CE, Strippoli MPF, Niggli F, Egger M, von der Weid NX. Cohort profile: the Swiss Childhood Cancer Survivor Study. *Submitted.*

Rebholz CE, Kuehni CE, Strippoli MPF, Rueegg CS, Michel G, Hengartner H, Bergstraesser E, von der Weid NX. Alcohol consumption and binge drinking in young adult childhood cancer survivors: a report from the Swiss Childhood Cancer Survivor Study. *Submitted.*

Project 5 – Follow-up care after childhood and young adult cancer (CCFU)

This is a survey of long-term survivors (≥5 years) of childhood cancer, oncologists, haematologists and family practitioners in Switzerland, to assess the current use of follow-up care and preferences / opinions for a future Swiss model of follow-up care.

Background: Treatment for cancer in children and young adults has greatly improved and most cases are being cured. However, more than 50% of survivors of childhood cancer suffer from late effects. To detect and treat late effects as early as possible it is important that survivors continue to visit follow-up care long after they have been cured from cancer. Various models of follow-up care have been described but so far none has been implemented in Switzerland. While follow-up care needs to be constantly updated according to the current status of research, it is also important that it is convenient for survivors to participate.

Objectives: 1) To compare the advantages and disadvantages of follow-up care models currently used in Europe. 2) To determine the current availability and use of follow-up care in survivors of childhood and young adult cancers in Switzerland. 3) To determine the advantages and disadvantages of follow-up care models as perceived by survivors, oncologists and family practitioners, and to compare their views and opinions.

Methods: For part 1, we invited 198 clinics and follow-up programmes in Europe to complete a questionnaire survey describing the follow-up care available at their institution. For part 2, we analysed the current use of follow-up care (*Michel et al. Psycho-Oncology 2010*) together with the psychological well-being in childhood cancer survivors (*Michel et al. Journal of Clinical Oncology 2010*) using data from the Swiss Childhood Cancer Survivor Study (SCCSS). In part 3, a questionnaire survey will assess opinions and perspectives on both currently used and desired optimal follow-up care. The sample includes childhood, adolescent and young adult cancer survivors who were diagnosed with cancer between 1990 and 2005 and aged under 25 years, who have survived for more than 5 years and who are currently aged 11 years and older. In addition, paediatric and adult oncologists and haematologists, and family practitioners will fill in a questionnaire.

Rationale and significance: This project provides an overview of the follow-up care used in Europe and will describe the preferences for follow-up care models in survivors, oncologists and family practitioners in Switzerland. Differences between the three groups will be determined in order to improve follow-up care in the future, adapting it to differing preferences. The project will provide the basis for the development of a standardised model of follow-up care for childhood cancer survivors in Switzerland.

Study Team

Applicant: Michel G. Institute of Social and Preventive Medicine, University of Bern.
Project team: Michel G, Kuehni CE, Egger M, Hohn A. Institute of Social and Preventive Medicine, University of Bern; Von der Weid NX. Paediatric Oncology, CHUV Lausanne; Niggli F. University Children's Hospital, Zurich.

Funding: Swiss National Science Foundation (Division Individual Funding "Ambizione" Grant No. PZ00P3_121682/1)

Collaborations

Eiser C, Greenfield D. Child and Family Research Group, University of Sheffield. Hjorth L, Skinner R, Haupt R, Hawkins M, Kremer L. PanCare (European network of professionals, survivors and their families established to ensure that every European survivor of childhood and adolescent cancer receives optimal long-term care)

Contact: Gisela Michel (michel@ispm.unibe.ch)

Publications

Michel G, Kuehni CE, Rebholz CE, Zimmermann K, Eiser C, Rueegg CS, von der Weid NX. Can health beliefs help explaining attendance to follow-up care? The Swiss Childhood Cancer Survivor Study. *Psycho-Oncology 2010; DOI: 10.1002/pon.1823*

Michel G, Greenfield D, Absolom K, Eiser C. Follow-up care after childhood and young adult cancer: Satisfaction and associations with coping style. *Psycho-Oncology 2010; DOI:10.1002/pon.1783*

Rebholz CE, von der Weid NX, Michel G. Niggli F, Kuehni CE. Follow-up care amongst long-term childhood cancer survivors: a report from the Swiss Childhood Cancer Survivor Study. *European Journal of Cancer 2011; 41:221-9.*

Michel G, Rebholz CE, von der Weid NX, Bergstraesser E, Kuehni CE. Psychological distress in adult childhood cancer survivors: the Swiss Childhood Cancer Survivor Study. *Journal of Clinical Oncology 2010; 28:1740-7.*

Project 6 – Risk of cancer and long-term mortality in children treated with Growth hormone: Swiss participation in the EU FP7 project "SAGhE"

Background: Since 1985 recombinant growth hormone (GH) has been available. Initially it was used to treat cases of primary severe growth hormone deficiency (GHD) but its use has since multiplied to include various indications where childhood short stature is not primarily due to deficient endogenous GH secretion, for instance Turner Syndrome, Prader-Willi Syndrome, children born short for gestational age (SGA), chronic renal failure and idiopathic short stature. Another important indication is childhood cancer. GHD is the most common endocrine late effect of cancer treatment in children, especially after brain tumours and cranial irradiation. Efficacy of GH in children with severe GHD is undisputed and short term safety during treatment is generally considered satisfactory. Data on efficacy for other indications, association with quality of life and long-term safety are scarce due to limited numbers of patients within individual countries. Several experimental studies have raised concerns with regards to cancer risk and long-term mortality. To overcome the problem of low numbers, an international consortium including investigators from eight different countries in addition to Switzerland was constituted to study "Safety and Appropriateness of Growth hormone treatments in Europe" (SAGhE).

Objectives: We aim to establish a cohort of young adults treated with GH in childhood due to different diagnoses, and to describe the indications and frequency of GH used for children in Switzerland since 1985; to assess the long-term efficacy and quality of life in adulthood after GH-treatment in childhood; and to investigate the long-term safety of GH-treatment in childhood, in particular the risk of cancer and mortality during child- and adulthood.

Methods: To identify all eligible patients, we will collect information from: a) patient lists of all paediatric endocrinology departments and practicing paediatric endocrinologists in Switzerland; b) databases: KIGS – Pfizer International Growth Database; databases of the SCCR, the Swiss Childhood Cancer Survivor Study and the Swiss Paediatric Renal Registry. Relevant data will be extracted from hospital records and registry databases. Assessment of quality of life will be done via questionnaire survey. The number of cancer diagnoses and mortality will be assessed by deterministic and probabilistic linkage of the databases with the cantonal cancer registries in Switzerland and with the mortality statistics of the Swiss Federal Statistical Office. For participants living in cantons not covered by a cancer registry, cancer outcomes will be assessed via questionnaire survey.
The risk of cancer and mortality in the cohort will be compared to the risk in the general population by calculating standardized incidence rates and standardized mortality rates. For diagnoses with increased baseline risks (childhood cancer survivors, chronic renal failure), the risk in GH-treated patients will be compared to the risk in untreated patients with similar diagnoses.

Rationale and significance: The project will describe the use of GH in Switzerland and analyse long-term safety in the frame of a high-quality international collaborative study. Results will be presented to the public, guidelines committees and health authorities and are likely to influence future recommendations for treatment with GH in children, particularly in children suffering from cancer. Furthermore, prospective data collection will be continued and will serve as a resource for future research.

Study Team

Applicants: Mullis P. University Children Hospital, Inselspital Bern, Department for Paediatric Endocrinology, Diabetology and Metabolism; Kuehni CE, Bohlius J. Institute of Social and Preventive Medicine, University of Bern; Grotzer M. University Chlidren's Hospital, Zurich; Clough-Gorr K. NICER, Institute of Social and Preventive Medicine, University of Zurich.
Project team: Sommer G, Karabulut F, Kuehni CE. Institute of Social and Preventive Medicine, University of Bern; Mullis P. University children hospital, Inselspital Bern, Department for Paediatric Endocrinology, Diabetology and Metabolism.

Funding: EU-FP7 call HEALTH-2007-3.1-5: Better use of medicines, Swiss Cancer League (Oncosuisse)

Contact: Grit Sommer (gsommer@ispm.unibe.ch)
Claudia Kuehni (kuehni@ispm.unibe.ch)

Publications: Expected for 2012

Project 7 – Childhood leukaemia and lymphoma: are incidence and survival in Switzerland associated with socio-economic status?

The research project aims to investigate the association of socio-economic status (SES) with the risk of developing childhood leukaemia or childhood lymphoma, and to explore whether the association is varying with the operational definition of socio-economic status.

Objectives: 1) To investigate the association of socio-economic status with the risk of developing childhood leukaemia or childhood lymphoma, and to explore whether the association is varying with the operational definition of socio-economic status. 2) To investigate the association of socio-economic status with the five-year survival rate for cases of childhood leukaemia or childhood lymphoma.

Methods: The two main aims are addressed by a case-control study design (for the association between SES and the risk of disease) and by a prospective cohort study design of the included cases (for potential differentials in mortality and survival). The study includes all cases of childhood leukaemia or lymphoma registered in the SCCR, who were diagnosed between 1991 and 2006 and were recorded either in the 1990 or in the year 2000 census (approximately 700 leukaemia and 300 lymphoma cases). Having been recorded in one of the censuses is necessary to obtain relevant information on the SES of the child's parents, i.e. profession and education. Other measures available from the census data include information on the living conditions, i.e. the number of rooms per person in the household and ownership of house or apartment. In addition, we use the recently developed Sotomo-Index, an area-based SES measure which is defined by the community in which a person lives (www.sotomo.geo.unizh.ch). To obtain the SES information from the census records we have developed and will use methodologically sound probabilistic record linkage procedures. For the case-control study we have selected for each case 10 control children from the two census rounds. We can thus include approximately 1000 cases and 10,000 control subjects in the case-control part of the study. Analysis is being performed by logistic regression and time-to-event analyses (life-table, Kaplan-Meier estimates and proportional hazards models).

Rationale and significance: Childhood leukaemia and childhood lymphoma comprise about half of all cancer diagnoses in children. Therefore, assessing SES as a risk factor for this subgroup is of public health relevance. Using the population-based childhood cancer registry in this study will provide accurate measures of risk for developing childhood leukaemia or lymphoma.

Study Team

Applicants: Zwahlen M, Kuehni CE, Egger M. Institute of Social and Preventive Medicine, University of Bern; Von der Weid NX. Paediatric Oncology, CHUV Lausanne.
Project team: Adam M. Swiss Tropical and Public Health Institute Basel; Zwahlen M, Kuehni CE, Spoerri A, Schmidlin K. Institute of Social and Preventive Medicine, University of Bern

Funding: Swiss Cancer League (Grant No. OCS 01869-02-2006)

Contact: Marcel Zwahlen (zwahlen@ispm.unibe.ch)

Publications

Adam M, Rebholz CE, Egger M, Zwahlen M, Kuehni CE. Childhood leukemia and socioeconomic status: what is the evidence? *Radiation Protection Dosimetry 2009; 132:246-54.*

Feller M, Adam M, Zwahlen M, Brazzola P, Niggli F, Kuehni CE for the Swiss Pediatric Oncology Group (SPOG) and the Swiss National Cohort (SNC). Family characteristics as risk factors for childhood acute lymphoblastic leukemia: a population-based case-control study. *PlosOne 2010; 5;e13156.*

Adam M, Spoerri A, Schmidlin K, Gumy-Pause F, Brazzola P, Kuehni CE, Zwahlen M for the Swiss Paediatric Oncology Group (SPOG) and the Swiss National Cohort Study Group (SNC). Socioeconomic status and childhood leukemia in Switzerland. *Submitted.*

Adam M, Schmidlin K, Spoerri A, Niggli F, Grotzer M, von der Weid N, Zwahlen M, Kuehni CE for the Swiss Paediatric Oncology Group (SPOG) and the Swiss National Cohort Study Group (SNC). Socio-economic differentials in childhood cancer survival in Switzerland. *Submitted.*

Project 8 – An international case-control study on brain tumours in children and adolescents – CEFALO

Background: It has been hypothesized that children could be more vulnerable to radio frequency electromagnetic field exposures from mobile telephones than adults, but no epidemiological studies of this potential association have been performed so far. The lack of knowledge causes conflicting recommendations from decision-makers, leading to anxiety and insecurity in the population. That is the reason why the WHO put a case-control study on radio frequency electromagnetic fields and childhood brain tumours as a high priority on their 2006 research agenda.

Objectives: The main goal of the study is to investigate whether the use of mobile telephones increases the risk of developing brain tumours for children or adolescents. In addition, our study will provide a comprehensive dataset to investigate other potential risk factors for childhood brain tumours.

Study design: The questions are being investigated by means of an international case-control study in Denmark, Norway, Sweden and Switzerland. Cases were identified through a combination of registry data and information from the wards treating the cases (e.g. Swiss Paediatric Oncology Group). All incident cases of brain tumour at age 7-19 years between May 2004 and April 2008 were invited to participate. In total, the study includes 550 cases of brain tumours in all participating countries, of which 100 originate from Switzerland. For each case, two control persons have been randomly selected from the general population, matched on age, sex and geographic region.

Exposure assessment: Information on the extent of exposure to radio frequency fields from mobile phones, and on other known and suspected risk factors for childhood brain tumours is obtained by means of computer assisted personal interviews conducted by an interviewer trained for this purpose. The interviews took place either at the hospital or at the study participant's home. Objective information on the frequency and duration of mobile phone use is being obtained from mobile phone operators and from the information stored in the telephone that is in current use.

Data analyses: The data are being analyzed using statistical methods for case-control studies, primarily via logistic regression models adjusted for potential confounders. In order to investigate potential gene-environment interactions, DNA from saliva samples is being extracted and analysed. Polymorphisms in genes that affect oxidative metabolism, detoxification of carcinogens, DNA stability and repair, or immune response, are candidates that might confer genetic susceptibility to brain tumours.

Rational and significance: Since the 1990s there has been a steep increase in the ownership of mobile phones and the amount of their use throughout the world. This increase has raised concerns about their possible detrimental health effects. Due to the proximity of mobile phones to the head during calls, brain tumours have been the primary concern. Further, recent studies indicate that children have higher energy absorption than adults and thus may be more vulnerable to mobile phone RF radiation. The lack of knowledge leads to anxiety and insecurity in the population. The WHO and the National Academies (USA) have put a case-control study on childhood brain tumours as a high priority on their research agenda on radio frequency electromagnetic fields. If mobile phone use is associated with an increased brain tumour risk, this is of high public health importance. With the exposure prevalence now reaching almost 100% in many countries worldwide, even a moderate association would cause a considerable number of additional cases attributable to mobile phone usage. Up to date, no studies are available that have specifically addressed the possible association between mobile phones and the risk of brain tumours among children and adolescents.

Study Team

Applicants: Röösli M. Swiss Tropical and Public Health Institute Basel; Kuehni CE. Institute of Social and Preventive Medicine, University of Bern; Grotzer M. University Children's Hospital, Zurich; Feychting M. Karolinska Institutet, Stockholm; Tynes T. Cancer Registry of Norway, Oslo; Von der Weid NX. Paediatric Oncology, CHUV Lausanne; Schuetz J. International Agency for Research on Cancer (IARC), Section of Environment and Radiation, Lyon, France.
Project Team: Aydin D, Röösli M, Jenni D, Rey D. Swiss Tropical and Public Health Institute Basel; Kuehni CE. Institute of Social and Preventive Medicine, University of Bern.

Funding: Swiss Federal Office of Public Health, Swiss Research Foundation on Mobile Communication and Swiss National Science Foundation (Grant No. PDFMP3_122873)

Contact: Martin Röösli (martin.roosli@unibas.ch)

Publications

Aydin D, Feychting M, Schüz J, Andersen TV, Poulsen AH, Prochazka M, Klæboe L, Kuehni CE, Tynes T, Röösli M. Impact of random and systematic recall errors and selection bias in case–control studies on mobile phone use and brain tumors in adolescents (CEFALO study). *Bioelectromagnetics 2011; doi: 10.1002/bem.20651.*

Aydin D, Feychting M, Schüz J, Tynes T, Andersen TV, Schmidt LS, Poulsen AH, Johansen C, Prochazka M, Birgitta Lannering, Klæboe L, Eggen T, Jenni D, Grotzer M, Von der Weid NX, Kuehni CE, Röösli M. Mobile phone use and risk of brain tumours in children and adolescents: a multicenter case-control study (CEFALO). *Submitted.*

5 Improvement of completeness and quality in 2009 - 2010

In a previous study comparing the cases registered in the SCCR with those registered in individual cantonal cancer registries for the years 1990 to 2004 we found that both the SCCR and the cantonal registries missed a certain proportion of cases only registered in one of the two databases.[12] To detect and register these missed cases in both registries (SCCR and cantonal) it is necessary to compare the two datasets and exchange data at regular intervals.

Collaboration with cantonal cancer registries

With the 11 cantonal cancer registries the SCCR has recently agreed on a standardized procedure for the identification and exchange of patient records missed in each registry. The procedure respects different situations in different cantons, e.g. regulations on data protection. The aim of the data exchange is to improve the quality and completeness of the information collected in both registries for children and young adults diagnosed with cancer at age 0-20 years (<21 years). The general authorization of the Federal Expert Commission for Professional Secrecy in Medical Research allows these exchanges.

The first data comparison was done retrospectively with all cases registered in each registry since data collection started. The comparison with data collected in the cantonal cancer registries of the cantons Fribourg, Geneva, Grisons & Glarus, Vaud, Valais, Neuchâtel and Zurich was completed by the end of 2010. A comparison with the remaining cantonal registries will be completed early in 2011.

Collaboration with pathology laboratories

In cantons without a cantonal cancer registry (e.g. Bern, Aargau, Thurgau) other sources of data need to be used to improve data quality and completeness in the SCCR. One way to find missed cases is to compare data with local pathology laboratories. In Bern, pathology laboratories were contacted and collaboration was established with the major laboratories (“Institute for Pathology” at the University of Bern and “Unilabs”).

Collaboration with pathology laboratories may also help to detect second tumours, which will be identified for different research projects.

Collaboration with the Swiss Federal Statistical Office

Collaboration was also established with the FSO. The FSO provides anonymised data on mortality in the population aged 0-25 years in Switzerland. This allows the SCCR to check and complete dates of death in its database and therefore to calculate survival time. Rarely, cases had only been diagnosed shortly before or just after death. Therefore this procedure allows the SCCR to register “death certificate only” cases (DCO).

Since 2010 the FSO also provides anonymised data on the hospitalisation of cases with cancer diagnoses in Swiss hospitals. According to ICD-10 diagnostic codes and the age at diagnosis, we are able to find hospitals other than SPOG centres which also treated childhood cancer cases. This allows the SCCR to contact the corresponding hospital and register these cases. In the past not all childhood cancer cases were treated in a specialized cancer care unit and still today many adolescents are treated in adult oncology centres.

12 Adam M, von der Weid NX, Michel G, Zwahlen M, Lutz JM, Probst-Hensch N, Niggli F, Kuehni CE. Access to specialized pediatric cancer care in Switzerland. Pediatric Blood & Cancer 2010; 54:721-7.

6 Publications

All articles published using SCCR data from January 2006 – April 2011 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.

Peer-reviewed publications

2011

1. Aydin D, Feychting M, Schüz J, Andersen TV, Poulsen AH, Prochazka M, Klaebo L, Kuehni CE, Tynes T, Röösli M. **Impact of random and systematic recall errors and of selection bias in case-control studies on mobile phone use and brain tumours in adolescents (CEFALO study)**. *Bioelectromagnetics 2011 doi: 10.1002/bem.20651.*
2. Rebholz CE, von der Weid NX, Michel G, Niggli FK, Kuehni CE for the Swiss Paediatric Oncology Group (SPOG). **Follow-up care amongst long-term childhood cancer survivors: a report from the Swiss Childhood Cancer Survivor Study**. *European Journal of Cancer 2011; 41:221-9.*
3. Marquis A, Strippoli MPF, Spycher BD, Rebholz CE, von der Weid NX, Kuehni CE for the Swiss Pediatric Oncology Group (SPOG). **Paracetamol, nonsteroidal anti-inflammatory drugs, and risk of asthma in adult survivors of childhood cancer.** *Journal of Allergy and Clinical Immunology 2011; 127:270-2.*

2010

4. Feller M, Adam M, Zwahlen M, Brazzola P, Niggli F, Kuehni CE for the Swiss Pediatric Oncology Group (SPOG) and the Swiss National Cohort (SNC). **Family characteristics as risk factors for childhood acute lymphoblastic leukemia: A population-based case-control study**. *PlosOne 2010; 5:e13156.*
5. Michel G, Kuehni CE, Rebholz CE, Zimmermann K, Eiser C, Rueegg CS, von der Weid NX for the Swiss Pediatric Oncology Group (SPOG). **Can health beliefs help explaining attendance to follow-up care? The Swiss Childhood Cancer Survivor Study**. *Psycho-Oncology 2010; doi:10.1002/pon.1823.*
6. Marquis A, Kuehni CE, Strippoli MPF, Kühne T, Brazzola P for the Swiss Pediatric Oncology Group (SPOG). **Sperm analysis of patients after successful treatment of childhood acute lymphoblastic leukemia with chemotherapy**. *Pediatric Blood & Cancer 2010; 55:208-10.*
7. Adam M, von der Weid NX, Michel G, Zwahlen M, Lutz JM, Probst-Hensch NM, Niggli F, Kuehni CE for the Swiss Pediatric Oncology Group (SPOG) and for the Swiss Association of Cancer Registries (ASRT). **Access to specialized pediatric cancer care in Switzerland**. *Pediatric Blood & Cancer 2010; 54:721-7.*
8. Michel G, Rebholz CE, von der Weid NX, Bergstraesser E, Kuehni CE for the Swiss Pediatric Oncology Group (SPOG). **Psychological distress in adult survivors of childhood cancer: the Swiss Childhood Cancer Survivor Study**. *Journal of Clinical Oncology 2010; 28:1740-8.*

2009

9. Adam M, Rebholz CE, Egger M, Zwahlen M, Kuehni CE. **Childhood leukaemia and socioeconomic status: what is the evidence?** *Radiation Protection Dosimetry 2009; 132:246-54.*

2008

10. Michel G, von der Weid NX, Zwahlen M, Redmond S, Strippoli MPF, Kuehni CE. **Incidence of childhood cancer in Switzerland: the Swiss Childhood Cancer Registry.** *Pediatric Blood & Cancer 2008; 50:46-51.*

2007

11. Michel G, von der Weid NX, Zwahlen M, Adam M, Rebholz CE, Kuehni CE. **The Swiss Childhood Cancer Registry: rationale, organisation and results for the years 2001-2005.** *Swiss Medical Weekly 2007; 137:502-9.*
12. Röösli M, Michel G, Kuehni CE, Spoerri A. **Cellular telephone use and time trends in brain tumour mortality in Switzerland from 1969 to 2002***. European Journal of Cancer Prevention 2007; 16:77-82.*

2006

13. Kuehni CE, Zwahlen M. Commentary: **Numerous, heterogeneous and often poor – the studies on childhood leukaemia and socioeconomic status***. International Journal of Epidemiology 2006; 35:384-5.*

Other publications

2010

1. Kuehni CE. **The Swiss Childhood Cancer Registry: from causes to outcomes**. *Schweizer Krebsbulletin 2010; 2:129-30.*

2009

2. Kuehni CE, Feller M, Egger M. **Response to: Sufficient statistical power for CANUPIS?** *Schweizer Krebsbulletin 2009; 4.09:301.*

2008

3. 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; 28:264-6.*
4. 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.*
5. 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.** *Bulletin des médecins suisses 2008; 89:117-9.*
6. Kuehni CE, von der Weid NX. **Das Schweizer Kinderkrebsregister als erstes nationales Krebsregister: Information der Ärzteschaft zur neuen Datenschutzsituation.** *Pediatrica 2008; 19:53-5.*
7. 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.** *Pediatrica 2008; 19:50-2.*

2005

8. von der Weid NX. **Spätfolgen nach Krebserkrankung und deren Therapie**. *Pädiatrie 2005; 3:20-22.*
9. Betts DR, Niggli FK. **Cytogenetics of childhood acute lymphoblastic leukaemia in Switzerland**. (A 10-Year Update). *Krebsbulletin 2005; 1-05:71-4.*

Reports

2011

1. Strippoli MPF, Kuehni CE. **Childhood Cancers**. In: Cancer in Switzerland – Situation and development from 1983 to 2007. *Neuchâtel: Federal statistical office (FSO); 2011*; p. 72-77.

2009

2. Kuehni CE, Michel G, Pyrlik M, Strippoli MPF, von der Weid NX. **The Swiss Childhood Cancer Registry. Annual Report 2007/2008**. *Bern: Institute of Social and Preventive Medicine, University of Bern; June 2009.*

2007

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

2005

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

5. Michel G, Sturdy M, Zwahlen M, Strippoli MPF, von der Weid NX, Kuehni CE. **Validating date and cause of death information in the Swiss Childhood Cancer Registry against death certificate information from the Swiss Federal Office of Statistics**. *Bern: Department of Social and Preventive Medicine, University of Bern; December 2005.*

7 Abbreviations

AML	Acute Myeloid Leukaemia
ALL	Acute Lymphoblastic Leukaemia
BMT	Bone Marrow Transplantation
CANUPIS	Childhood Cancer and Nuclear Power Plants in Switzerland
CCFU	Childhood Cancer Follow-up study
CHUV	Centre Hospitalier Universitaire Vaudois
CNS	Central Nervous System
DNA	Deoxyribonucleic Acid
EBMT	The European Group for Blood and Marrow Transplantation
ENCR	European Network of Cancer Registries
FOPH	Federal Office of Public Health
FSO	Federal Statistical Office
GCCR	German Childhood Cancer Registry, Mainz, Germany
GH	Growth Hormone
GHD	Growth Hormone Deficiency
GIS	Geographic Information System
HUG	Hôpitaux Universitaires de Genève
HRQoL	Health Related Quality of Life
IACR	International Association of Cancer Registries
IARC	International Association of Research in Cancer
ICCC-3	International Classification of Childhood Cancer, Third revision
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth revision
ICD-O-3	International Statistical Classification of Diseases for Oncology, Third edition
ISPM	Institute of Social and Preventive Medicine, Bern
LCH	Langerhans Cell Histiocytosis
NBR	National Birth Registry
NICER	National Institute for Cancer Epidemiology and Registration, Zurich
NPP	Nuclear Power Plants
NRCT	National Registry of Childhood Tumours, Oxford, England
PanCare	Pan-European Network for Care of Survivors after Childhood and Adolescent Cancers
PNET	Primitive Neuroectodermal Tumour
RF	Radio Frequency
SAGhE	Safety and Appropriateness of Growth Hormone Treatment in Europe
SCCR	Swiss Childhood Cancer Registry

Abbreviations - continued

SCCSS	Swiss Childhood Cancer Survivor Study
SES	Socio-Economic Status
SGA	Short for Gestational Age
SNC	Swiss National Cohort
SPOG	Swiss Paediatric Oncology Group
SurFup	PanCare Survivor Care and Follow-up Study
STS	Soft Tissue Sarcoma
UKBB	Universitätskinderspital beider Basel
WHO	World Health Organization

8 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.[13] It applies the rules, nomenclature and codes (morphology, topography and behaviour) of the ICD-O-3. Furthermore, 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. leukaemias 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. Most childhood cancer registries only use level one and two. 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)[14] 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 leukaemias. In contrast to the ICD-10 classification, 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. 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)[15] 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-O (-2).

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

14 World Health Organization. International Statistical Classification of Diseases for Oncology - Third Edition (ICD-O-3). Geneva: World Health Organization; 2000.

15 World Health Organization. International Statistical Classification of Diseases and Related Health Problems - Tenth Revision. Geneva: World Health Organization; 1993.