Peer reviewed article

The Swiss Childhood Cancer Registry: rationale, organisation and results for the years 2001–2005[1]

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Summary

Questions under study: Childhood cancer is a rare but severe disease. Therefore central registration of all cases is essential for surveillance and management. This paper describes the methodology and basic results of the Swiss Childhood Cancer Registry (SCCR).

Methods: The SCCR was established in 1976, originally as a national hospital-based registry of childhood malignancies. All 9 paediatric oncology-haematology clinics in Switzerland provide baseline and follow-up information on all children diagnosed with cancer. These data are registered centrally and diagnoses are coded according to the International Classification of Childhood Cancer.

Results: From 2001-2005, 887 cases of childhood cancer in Swiss residents under the age of 15 years were registered in the SCCR. Of these, 281 (31.7%) were leukaemias, 223 (24.0%) were CNS tumours, and 116 (13.1%) were lymphomas. The age-standardised annual incidence per 1 Million person-years (age below 15 years; world standardisation) was 154.0 (95% CI 143.7–164.3; N = 887). The incidence was higher for boys (170.2, 155.0–185.4; N = 501) than for girls (136.9, 123.0-150.8; N = 386).

Conclusion: The close collaboration between all paediatric oncologists-haematologists in Switzerland and a university department allowed the creation of a national population-based cancer registry with detailed clinical information. The SCCR produces cancer type specific incidence and survival estimates and allows the development of nested research projects on childhood cancer aetiology, management and outcome, both on a national and on an international level.

Key words: childhood cancer; incidence; survival; neoplasms; cancer registry

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Introduction

Childhood cancer is a rare disease with fewer than 1% of all cancers in industrialised countries occurring in children younger than 15 years of age [1]. Tumour types in children are diverse, many originating from embryonal tissues [2], and differ from those in adults, where carcinomas predominate. Albeit its low absolute incidence and despite dramatic therapeutic improvements, childhood cancer remains the second most common cause of death in childhood in Switzerland [3]. Childhood cancer also accounts for a high burden of long-term disability caused by the late effects of the cancer itself or its therapy [4–7]. The rarity of the disease in combination with its severity calls for a central registration of all cases in national and international databases. These allow time trends in incidence to be monitored, con-

Abbreviations used in the text:

95%CI	95% Confidence Interval
ACCIS	Automated childhood cancer information system
ASI	Age-standardised incidence
ASRT	Association of Swiss Cancer Registries
CNS	Central nervous system
ENCR	European Network of Cancer Registries
IACR	International Association of Cancer Registries
ICCC-3	International Classification of Childhood Cancer, 3rd edition
ICD-O-3	International Classification of Diseases for Oncology, 3rd edition
LCH	Langerhans cell histiocytosis
SCCR	Swiss Childhood Cancer Registry
SPOG	Swiss Paediatric Oncology Group
DCO	Death certificate only

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tributing to the identification of causes and the study of long-term outcome.

Specialised childhood cancer registries with national coverage exist in Germany, the UK and a few other countries [8–10]. In Switzerland, cancer registration for patients of all ages is done in 13 cantons covering 58% of the Swiss population (www.asrt.ch [11]). Children constitute only a small fraction of cases in these cantonal general cancer registries and information on clinical presentation, treatment and outcome is limited. For this reason, the Swiss Paediatric Oncology Group (SPOG) initiated a nationwide registry of childhood malignancies in 1976, the Swiss Childhood Cancer Registry (SCCR; www.kinderkrebsregister.ch [12]).

Historical background

During the first four years of its operation only patients entered into clinical trials were registered. From 1981 other patients were also included. In 1992, the paper-based registry was transferred to an electronic database and active long-term follow-up with registration of late effects was introduced. In 2004, the data centre of the SCCR was relocated to the Institute of Social and Preventive Medicine at the University of Berne. From originally being a hospital-based registry, the database and methodology were completely restructured in accordance with international recommendations [2, 13, 14] and all diagnoses were coded according to current classification systems [2, 15, 16]. The SCCR was admitted as an associate member of the International Association of Cancer Registries (IACR) and the European Network of Cancer Registries (ENCR) in February 2005.

Purpose and objectives of the SCCR

The SCCR collects data on diagnosis, clinical presentation, treatment and outcome of all paediatric cancer cases resident in Switzerland, aiming to: 1) provide national population-based data on incidence, survival, time trends and regional differences of childhood cancer; 2) contribute to the detection of environmental and genetic risk factors for childhood cancer and develop preventive strategies in nested studies and international projects; 3) assess long-term outcome and late effects of cancer treatments and help to develop strategies to avoid or mitigate these; 4) provide data for health care evaluation, planning and quality control.

For rare tumours the total numbers registered in Switzerland are low and international collaboration is essential. The SCCR therefore participates in international research projects, for instance the CEFALO project studying causes of brain tumours in children and adolescents (http://www.research.unibe.ch/abstracts/A_65962086.html).

This paper presents the methodology of the Swiss Childhood Cancer Registry, selected results from the past years of operation and a short overview of current and future developments.

Materials and methods

Case definitions

The SCCR aims to achieve complete registration of malignant solid tumours, leukaemias and lymphomas (including myelodysplastic syndromes), central nervous system (CNS) tumours (both malignant and benign) and Langerhans cell and other histiocytoses among children under 16 years of age resident in Switzerland. In this paper, we present data for children less than 15 years of age. In 2006, diseases for all cases in the database have been classified according to the International Classification of Diseases for Oncology, third edition (ICD-O-3) [15], and the International Classification of Childhood Cancer, third edition (ICCC-3) [2].

Population and reporting sources

All children aged less than 16 years who are diagnosed or treated in one of the nine paediatric oncology-haematology units in Switzerland are reported to the SCCR. These clinics, five of which are linked to a University Hospital, are located in Aarau, Basel, Berne, Geneva, Lausanne, Locarno, Lucerne, St. Gallen and Zurich. A clinical research assistant in each paediatric oncology-haematology clinic notifies new cases to the data centre in Berne, using a standard notification form and provides follow-up data from clinical visits for at least 5 to10 years.

Data collected

The initial patient notification form includes patient identification data (names, dates of birth, diagnosis, gender, address), information on prior relevant diseases and diagnostic details (exact diagnosis, localisation, morphology, behaviour, staging and metastases). Subsequently detailed data on treatment and outcome (including relapses, late-effects, second tumours or death) are reported in yearly intervals. Detailed information on the collected data is available in the annual reports (www.kinderkrebsregister.ch) [12].

Confidentiality and data protection

The SCCR has been permitted to work with non-anonymised data by the Swiss expert commission for data protection in medical research. Data are collected in a password-protected access database on a stand-alone computer and analyses are performed with anonymised data only. Informed consent to collect and transfer data to the data centre has been obtained from parents and children since 2003, the other patients have been informed and given the option to have their data anonymised (currently about 4% refuse consent).

Data quality

Close collaboration between all paediatric oncologists-haematologists in the SPOG and the small number of treating institutions enable a timely registration with very short delays in exchange of data. Incident cases are reported to the SCCR within two months of diagnosis. The SCCR maintains close contacts with local clinical research assistants and clinicians to ensure sustained high data quality. In 94% of the patients the diagnosis is verified by a cytological or histological analysis. For the period under study the mortality database was not accessed, and therefore no death certificate only (DCO) cases were reported.

At the data centre, details from each patient are manually checked for completeness, plausibility and consistency. Automatic procedures provided by IACR and ACCIS (Automated childhood cancer information system) have been used annually since 2003. A physician codes the diagnoses and enters data into the electronic database. Ambiguities are resolved in collaboration with the relevant paediatric oncology-haematology clinic. This includes verifying data for former patients in hospital case records where necessary. Data are fed back to the clinics through annual reports and on demand through data extraction for individual clinics and embedded studies.

Statistical analysis

SCCR data were analysed at the data centre in Berne, with diagnoses categorised according to the ICCC-3 [2]. Detailed results are presented for Swiss residents aged <15 years at diagnosis who were diagnosed with cancer in the years 2001–2005 (N = 887). Incidence rates were calculated using standard methods (average annual number of cases per 1 Mio person-years). The denominator data (person-years at risk) used to calculate incidence come from the Swiss Federal Statistical Office [17]. For the five calendar years considered, person-years at risk for boys and girls respectively were 185,300 and 175,434 for infants, 763,936 and 721,582 for 1–4 year olds, 1,043,624 and 988,918 for 5-9 year olds and 1,118,768 and 1,061,246 for 10–14 year olds [17]. The 95% confidence intervals (95%CI) for the incidence were calculated assuming the counts to be Poisson distributed [18]. All the statistical analyses were performed using STATA 8.2 software for Windows (STATA Corporation, Austin, Texas).

Results

Overall registry data

Between January 1976 and December 2005 a total of 5009 cases of childhood cancer had been registered in the SCCR, 4699 of them in children aged less than 15 years. Eighty-seven percent of the children (4363/5009) were Swiss residents at the time of diagnosis (4085 below 15 years). Of the 5009 patients, 1204 (24.0%) were reported to have died (1042/4363 (23.9%) of Swiss residents), and 882 (17.2%) have been lost to follow-up (727/4363 (16.7%) of the Swiss residents).

Childhood cancer between 2001 and 2005

For all subsequent analyses we included only Swiss residents aged <15 years at diagnosis and diagnosed between 1 January 2001 and 31 December 2005 with cancer according to ICCC-3 (table 1). For all malignancies (excluding Langerhans cell histiocytoses (LCH)) the age-standardised annual incidence per 1 Mio person-years between 2001–2005 was 154.0 (95% CI 143.7–164.3), higher for boys (170.2, 155.0–185.4) than for girls (136.9, 123.0–150.8). The incidence in the first 5 years of life (211.2, 191.3–233.3) was nearly twice as high as in the age group 5 to 14 years (118.0, 108.1–128.8, figure 1). The cumulative risk of developing cancer within the first 15 years of life was 2240.5/1,000,000 and the median age at diagnosis was 6.0 years.

The most common diagnosis in Switzerland was leukaemia, representing 31.7% of all registered malignancies in 2001–2005 coded according to ICCC-3 (table 1). Lymphomas constituted 13.1% of all paediatric malignancies and showed a marked difference in incidence between genders, boys being 2.2 times more often affected than girls. CNS tumours accounted for 24.0% of cases. While the most common tumour in infancy was neuroblastoma (32%), leukaemias peaked at age 1–4 years (1–4 year: 43.8%; 5–9 years: 33.3%; 10–14 years: 24.8%). After age 10 years, embryonal tumours such as retinoblastoma, nephroblastoma and hepatoblastoma almost disappeared, whereas other cancers became more frequent, notably lymphomas (23.7%) and bone tumours (10.9%). Solid tumours (not including lymphomas) accounted for 53.2% of cases recorded between 2001 and 2005; 91% of all cases (excluding LCH) were malignant tumours; the remaining 9% were non-malignant CNS tumours.

Discussion

This paper describes the evolution of the Swiss Childhood Cancer Registry from its origin as a hospital-based case collection into a national population-based childhood cancer registry with long-term follow-up. We describe the methodology and give incidence data for the last 5-year period. Between 2001 and 2005, about 180 new cases were registered every year in Swiss residents aged 0 to 14 years, giving an age-standardised incidence of childhood cancer of 154.0 per 1 Mio person-years (154/Mio). The relative frequency of various malignancies and the age-sex distribution are comparable to other European countries [19, 20], with leukaemias comprising about one third and CNS tumours about one fourth of all tumours.

Table 1

Frequencies, sex-ratios and number of cases per age-group of childhood malignancies registered in the SCCR (Swiss children below 15 years of age, diagnosed between 2001–2005 respectively; diagnoses classified according to ICCC-3*[2])

						Age groups (in years)					Crude incidence	Age standardized incidence
	Number	%**	Girls	Boys	Sex ratio (Boys:Girls)	<1	1–4	5–9	10–14	Median Age	per 1 Mio per annum	per 1 Mio per annum
Total (excluding Langerhans cell histiocytosis)	887	100.0	386	501	1.3	100	290	231	266	6.0	146.4	154.0
Total (including Langerhans cell histiocytosis)	911		396	515	1.3	106	295	240	270	6.0		
I All leukaemias	**281**	**31.7**	**126**	**155**	**1.2**	**11**	**127**	**77**	**66**	**5.1**	**46.4**	**49.8**
Acute lymphoblastic leukaemias	222	79.0	102	120	1.2	6	107	65	44	4.9	36.6	39.8
Acute myeloid leukaemias	40	14.2	15	25	1.7	3	14	7	16	7.1	6.6	6.8
Myelodysplastic syndrome	13	4.6	7	6	0.9	2	2	4	5	8.2	2.1	2.1
Unspecified and other specified leukaemias	6	2.1	2	4	2.0	0	4	1	1	3.5	1.0	1.1
II Lymphomas	**116**	**13.1**	**36**	**80**	**2.2**	**5**	**17**	**31**	**63**	**10.7**	**19.1**	**17.9**
Hodgkin's lymphomas	42	36.2	19	23	1.2	0	3	7	32	11.8	6.9	6.0
Non-Hodgkin's lymphomas (except Burkitt lymphoma)	57	49.1	12	45	3.8	2	10	20	25	9.0	9.4	9.0
Burkitt lymphoma	12	10.3	3	9	3.0	0	3	4	5	8.6	2.0	1.9
Misc. lymphoreticular neoplasms	4	3.4	1	3	3.0	3	1	0	0	0.9	0.7	0.9
Unspecified lymphomas	1	0.9	1	0	0.0	0	0	0	1	13.6	0.2	0.1
III CNS neoplasms	**213**	**24.0**	**102**	**111**	**1.1**	**19**	**61**	**78**	**55**	**6.9**	**35.2**	**36.5**
Ependymomas and choroids plexus tumours	20	9.4	9	11	1.2	6	10	1	3	2.1	3.3	3.9
Astrocytomas	68	31.9	33	35	1.1	0	17	33	18	7.6	11.2	11.2
Intracranial and intraspinal embryonal tumours	58	27.2	20	38	1.9	11	20	18	9	4.3	9.6	10.6
Other gliomas	26	12.2	16	10	0.6	2	8	14	2	5.8	4.3	4.6
Other specified intracranial and intraspinal neoplasms	40	18.8	23	17	0.7	0	6	11	23	10.6	6.6	6.1
Unspecified intracranial and intraspinal neoplasms	1	0.5	1	0	0.0	0	0	1	0	9.5	0.2	0.2
IV Neuroblastoma	**54**	**6.0**	**27**	**27**	**1.0**	**32**	**18**	**3**	**1**	**0.6**	**8.7**	**11.2**
Neuroblastoma and Ganglioneuroblastoma	54	100.0	27	27	1.0	32	18	3	1	0.6	8.7	11.2
V Retinoblastomas	**21**	**2.4**	**9**	**12**	**1.3**	**12**	**7**	**2**	**0**	**0.9**	**3.5**	**4.4**
VI Renal tumours	**46**	**5.2**	**18**	**28**	**1.6**	**7**	**28**	**9**	**2**	**2.4**	**7.6**	**9.0**
Nephroblastomas and other non-epithelial renal tumours	46	100.0	18	28	1.6	7	28	9	2	2.4	7.6	9.0
VII Liver tumours	**9**	**1.0**	**0**	**9**		**2**	**4**	**0**	**3**	**1.5**	**1.5**	**1.7**
Hepatoblastomas	7	77.8	0	7		2	4	0	1	1.2	1.2	1.4
Hepatocellular carcinomas	2	22.2	0	2		0	0	0	2	14.2	0.3	0.3
VIII Malignant bone tumours	**52**	**5.9**	**26**	**26**	**1.0**	**0**	**5**	**18**	**29**	**10.2**	**8.6**	**7.8**
Osteosarcomas	28	53.8	14	14	1.0	0	3	8	17	10.9	4.6	4.2
Chondrosarcomas												0.0
Ewing tumours and related sarcomas of bone	24	46.2	12	12	1.0	0	2	10	12	9.9	4.0	3.6
IX Soft tissue sarcomas	**53**	**6.0**	**21**	**32**	**1.5**	**6**	**17**	**9**	**21**	**6.6**	**8.7**	**9.1**
Rhabdomyosarcomas	32	60.4	11	21	1.9	3	13	5	11	5.0	5.3	5.6
Fibrosarcomas	4	7.5	2	2	1.0	1	1	1	1	5.2	0.7	0.7
Other specified soft tissue sarcomas	10	18.9	3	7	2.3	0	3	0	7	12.2	1.7	1.6
Unspecified soft tissue sarcomas	7	13.2	5	2	0.4	2	0	3	2	6.6	1.2	1.2

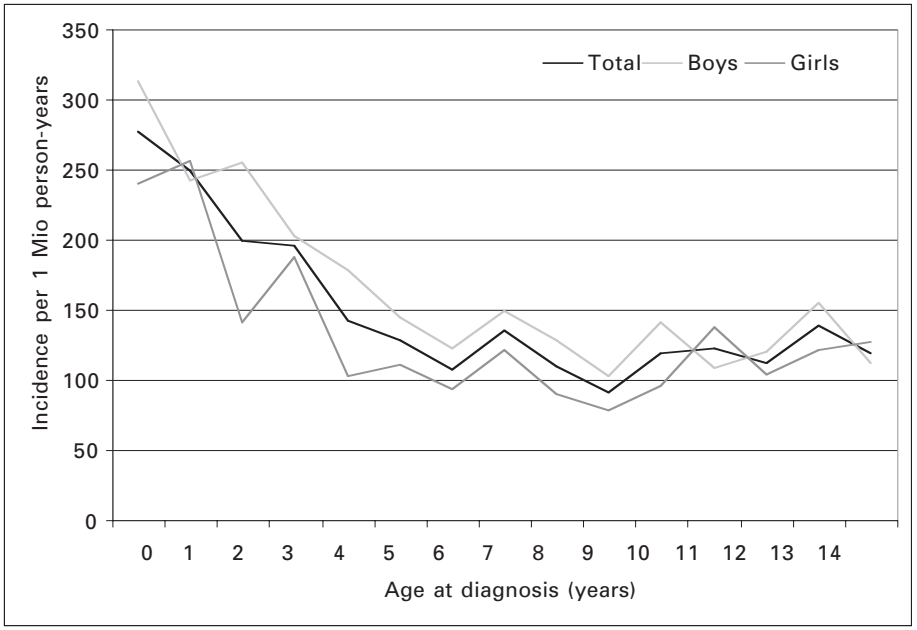
Table 1 (continued).

						Age groups (in years)					Crude incidence	Age standardized incidence
	Number	%**	Girls	Boys	Sex ratio (Boys:Girls)	<1	1–4	5–9	10–14	Median Age	per 1 Mio per annum	per 1 Mio per annum
X Germ cell tumours	**25**	**2.8**	**14**	**11**	**0.8**	**5**	**3**	**3**	**14**	**10.3**	**4.1**	**4.0**
Intracranial and intraspinal germ cell tumours	7	28.0	2	5	2.5	0	0	3	4	10.3	1.2	1.0
Malignant extra-cranial and extra-gonadal tumours	7	28.0	6	1	0.2	4	1	0	2	1.0	1.2	1.3
Malignant gonadal germ cell tumours	10	40.0	5	5	1.0	1	2	0	7	12.6	1.7	1.6
Gonadal carcinomas	1	4.0	1	0	0.0	0	0	0	1	13.9	0.2	0.1
XI Other unspecified carcinomas	**16**	**1.8**	**7**	**9**	**1.3**	**1**	**3**	**1**	**11**	**11.4**	**2.6**	**2.5**
Adrenocortical carcinomas	1	6.3	0	1		0	1	0	0	2.0	0.2	0.2
Thyroid carcinomas	8	50.0	3	5	1.7	0	0	0	8	12.1	1.3	1.1
Malignant melanomas	3	18.8	2	1	0.5	1	0	0	2	11.6	0.5	0.5
Skin carcinomas	1	6.3	0	1		0	1	0	0	2.6	0.2	0.2
Other unspecified carcinomas	3	18.8	2	1	0.5	0	1	1	1	8.9	0.5	0.5
XII Other malignant diseases	**1**	**0.1**	**0**	**1**		**0**	**0**	**0**	**1**	**12.9**	**0.2**	**0.1**
Other specified malignant tumours	1	100.0	0	1		0	0	0	1	12.9	0.2	0.1
Langerhans Cell Histiocytosis	**24**		**10**	**14**	**1.4**	**6**	**5**	**9**	**4**	**5.8**	**4.0**	**4.3**

* International Classification of Childhood Cancer – 3rd Edition
** for the calculation of the relative frequency all malignancies coded according to the ICCC-3 were included, excluding Langerhans Cell Histiocytoses

Figure 1

Gender and age-specific incidence rate of childhood malignancies registered in the SCCR (Swiss children diagnosed between 2001–2005).



Incidence of childhood cancer in Switzerland

Our results for incidence of childhood cancer in Switzerland are comparable to published data from neighbouring countries. The most comprehensive incidence data for all European countries, based on information from ACCIS have been recently published for the decade 1988–97. For the time period 1993-1997 overall incidence of childhood cancer in Europe was 141/Mio [21]. Incidence was lower (134/Mio) in the British Islands and higher in the Northern (164/Mio) and Southern (162/Mio) European countries.

More recent data, which can be directly compared to our results have only been published by a few countries: e.g. the German Childhood Cancer Registry (GCCR) [22], which has a comparable methodology to the SCCR, or the United Kingdom Childhood Cancer Research Group (UKCCRG) [23]. The total age-standardised incidence of childhood cancer in residents aged 0–14 years was slightly higher in Switzerland (2001–2005) than in the UK (1991–2000) and Germany (2000–2004): SCCR: 154/Mio, 95%CI: 143.7–164.3; UKCCRG: 139/Mio; GCCR: 147/Mio).

For leukaemias (SCCR: 46.4/Mio; UKCCRG: 45.5/Mio: GCCR: 48/Mio), lymphomas (SCCR: 19.1/Mio; UKCCRG: 12.5/Mio: GCCR: 17/Mio), CNS tumours (SCCR: 35.2/Mio; UKCCRG: 33.5/Mio: GCCR: 32/Mio) and neuroblastoma (SCCR: 8.7/Mio; UKCCRG: 9.3/Mio: GCCR: 12/Mio) the standardised incidence was similar in the three countries. Incidence of LHC was comparable in Germany (SCCR: 4.3/Mio; 95%CI: 2.6–6.0; GCCR: 6/Mio).

Incidence in the SCCR was also similar to published data from the Swiss Cantonal Cancer Registries (ASRT; covering 58% of the Swiss population) from 2001–2003 [24]: incidence at age 0–4 years in the SCCR was 237/Mio in males and 184/Mio in females, compared to 205/Mio and 165/Mio respectively in the ASRT. For the age group 5–9 years, the respective incidence for boys and girls was 128/Mio and 98/Mio in the SCCR, and 130/Mio and 94/Mio in the ASRT; and for 10–14 year old boys and girls the incidence was 127/Mio and 117/Mio in the SCCR and 128/Mio and 130/Mio in the ASRT.

Strengths and weaknesses of the SCCR

The evolution of the SCCR from a hospital-based case collection to a national population-based cohort study explains most of its weaknesses but also its strengths. To begin with the latter, the SCCR distinguishes itself through a close collaboration with all paediatric oncologists-haematologists in Switzerland. Usually, children with cancer receive treatment in one of only nine paediatric oncology-haematology centres. Only these centres, united in the SPOG, can provide optimal paediatric care, are staffed by specialised Paediatric Oncologists/Haematologists, are recognized centres for participation in international multi-centre clinical studies and can provide adequate insurance coverage. We therefore assume that the large majority of paediatric cancer cases in Switzerland are treated in - or have at least been seen at – one of these clinics. We cannot, however, exclude the possibility that a small minority of patients is being missed, such as some adolescents aged 14–15 years, some children with benign CNS tumours treated by surgery alone or cases only diagnosed at autopsy.

The close collaboration with the clinical centres also assures timeliness of registration, fast and straightforward feed-back to the centres, long-term follow-up data and high quality of the collected information. Data extraction for clinical studies in the referring centres, individual feed-back and annual reports enhance cooperation between the registry and treating physicians. As an additional aspect of interest the SCCR includes registration of cases with LCH. LCH is not classified as a malignant disease according to ICD-O-3, but has a high incidence of late effects [25] and a relatively poor survival rate that has increased from 57% for the period 1954–1968 to 74% for the period 1985–1998 [26].

A potential problem for the SCCR is completeness of registration. Until now, cases were notified mainly through physicians and clinical research assistants from all paediatric oncology-haematology units in Switzerland. Deaths were ascertained via long-term follow-up of patients or their paediatricians or general practitioners. Other databases, such as mortality statistics, pathology reports or archives from other hospitals were not accessed. However, the fact that incidence is similar to published incidence data from cantonal cancer registries and from the neighbouring countries France, Germany and Italy [27–30] suggests that the SCCR includes the vast majority of cases. Even CNS tumours, a problematic diagnostic group in many paediatric cancer registries [29, 31, 32] seem to be well covered, amounting in 2001–2005 to 24% of all cancers. A first study in the 1980s compared completeness of the SCCR to cantonal general cancer registries, mortality statistics and hospital archives. This showed that in 1985-88 the SCCR included 91% of all leukaemia cases recorded by the six existing cantonal registries and 80% of deaths due to childhood leukaemia in the mortality statistics in 1989 [33]. Based on these considerations, we assume that the SCCR currently captures at least 90% of all leukaemia cases and solid malignancies in Switzerland. Currently (2006–2008) completeness of data on incidence and mortality in the SCCR is being validated by linkage with datasets from the Association of Swiss Cancer Registries and national mortality statistics, and information from hospital archives, pathology and cytogenetics laboratories.

Outlook and future developments

Several ongoing research projects take advantage of the structure and data of the SCCR. A brief description of the projects is given below.

Long-term outcome and late effects: Improved survival rates from childhood cancer [34, 35] result in a growing population of long-term survivors. Many of them suffer from late effects of the cancer itself and its therapy, including late mortality, somatic health effects and impact on quality of life and on social integration [6, 7, 36, 37]. It is therefore essential to know how to predict, prevent and mitigate adverse outcomes among these young adults. A first large follow-up study of children and adolescents surviving disease-free at least 5 years from diagnosis was performed by von der Weid et al between 1990 and 1994. This study showed that in total, 67% of patients suffered from late effects depending on the type of tumour, with brain tumour survivors showing the worst outcome [38]. Even in the most common cancer, acute lymphoblastic leukaemia, 17% of the survivors had moderate or severe somatic or neuropsychological sequelae [5]. Risk factors for adverse outcomes included type of tumour [38], cranial irradiation, female sex, young age at diagnosis [5, 39] and non-inclu-

sion in a clinical trial [40, 41]. A second long-term outcome study started in 2006, which includes all 2665 patients diagnosed with a malignant tumour or CNS tumour at age <16 years before April 2002, who were Swiss residents at the time of diagnosis and who survived at least five years.

Long-term medical care: Another project evaluates quality of long-term medical care of cancer survivors in Switzerland. Many late effects have a better prognosis if diagnosed and treated early. Regular follow-up by professionals with specific knowledge is therefore essential to prevent, alleviate and treat these problems [42]. Until recently, this follow-up was provided mainly by paediatric oncologists/haematologists, but with growing numbers of long-term survivors, limited financial resources and aging of survivors this becomes impractical. Experience from abroad shows that medical care in older survivors is often unsatisfactory [43]. A clinical protocol for long-term follow-up of childhood cancer survivors in Switzerland has been developed [44] and the ongoing study will show how it has been implemented.

Risk factors for brain tumours: The SCCR takes part in the international study on risk factors of CNS tumours in children and adolescents (CEFALO), which pays special attention to exposure to mobile phones. As a side effect, the study is likely to improve completeness of registration of CNS tumours in the SCCR in future because it establishes a close collaboration with neurosurgeons, neurologists and oncologists caring for adolescent patients with CNS tumours [45].

In conclusion, the Swiss Childhood Cancer Registry evolved from a hospital-based case collection with detailed clinical information to a national population-based registry with long-term follow-up, containing a wide range of information on incidence, survival and late effects of childhood cancer. As such, the SCCR has accomplished a challenging task because Switzerland is a country, characterised by a heterogeneity of health care services and surveillance systems due to relative independence of individual cantons in managing their health care policy. This example might help to show the way for similar undertakings in other paediatric or adult diseases. Currently, the SCCR database and its nested research projects provide a valuable resource for national and international research on childhood cancer.

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