Completeness of the Swiss Childhood Cancer Registry
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Background & Aim
The Swiss Childhood Cancer Registry (SCCR), created in 1976 by the Swiss Paediatric Oncology Group (SPOG), includes all patients diagnosed and treated in one of the nine centres for paediatric oncology-haematology in Switzerland (Aarau, Berne, Basel, Geneva, Lausanne, Lucerne, St.Gallen, Ticino, Zurich) and is currently being reorganized to become a population-based registry. The general population-based cantonal cancer registries are organised in the Swiss Association of Cancer Registries (ASRT), which exist in nine cantons, covering 4.2 Millions of the Swiss population (56%).

The aim of the project was to evaluate the completeness of case registration in the SCCR registry in comparison with cantonal cancer registries. Furthermore, we tried to identify factors associated with missing registration.

Methods
For the linkage dataset we included all children aged <16 years at diagnosis with leukaemias, lymphomas, malignant solid tumours and all CNS tumours classified according to ICCC¹ and diagnosed between 1990-2004.

We compared children registered in the SCCR against records in the cantonal registries using SALI². For the analyses, only linked patients (found in both registries) and patients not found in the SCCR were included.

The proportion of linked cases was calculated and analysed according to age at incidence and year of diagnosis.

Results
In the result section we show the successfully linked records per total number of records in the cantonal registry, including the datasets of the cantonal registries of Geneva / St.Gallen & Appenzell / Ticino. In a next step the datasets of the other 6 registries (Basel / Grisons&Glarus / Neuchâtel / Valais / Vaud / Zurich) will be included in the analyses.

First results, analysing the linkage with 3 cantonal cancer registries, show that 84% of the cases registered in the ASRT can also be found in the SCCR.

Completeness of the SCCR improved over time from between 66% to 68% in the time period 1990-1994 to 78%, 91% and 96% in the time period 2000-2004.

In the age groups 0-4, 5-9 and 10-13 years, 94%, 87% and 84% of cases were registered in the SCCR. In adolescents (aged 14-15 years) a larger proportion of cases were missing with an average of only 52% linked cases.

Conclusions
- These preliminary results suggest that completeness of case registration in the SCCR was unsatisfactory in the early 1990ies, especially for older children, with less than 70% of all incident childhood cancer cases being registered in the SCCR.
- The patient information registration improved over time in the last 10 years (time periods: 1995-1999 and 2000-2004) with a proportion of 90%, respectively 88% registered cases.
- The most important reason for not being registered in the SCCR was the age of the child. A significant proportion of adolescents aged 14-15 years was not treated in a paediatric haematology-oncology clinic, and therefore not registered in the SCCR.

References
1 Stefanova-Foucher et al.: Cancer 2005, 103:1457-1467