



# 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 ICC3<sup>1</sup> and diagnosed between 1990-2004.

We compared children registered in the SCCR against records in the cantonal registries using SALI<sup>2</sup>.

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.

## Outlook

- We will extend the study by including datasets of the 6 other cantonal cancer registries.
- Cases which are found to be missing in the SCCR will be analysed in detail to identify the reasons for non-registration.
- Based on the results of this study, the SCCR will develop a strategy for improving case registration in future.

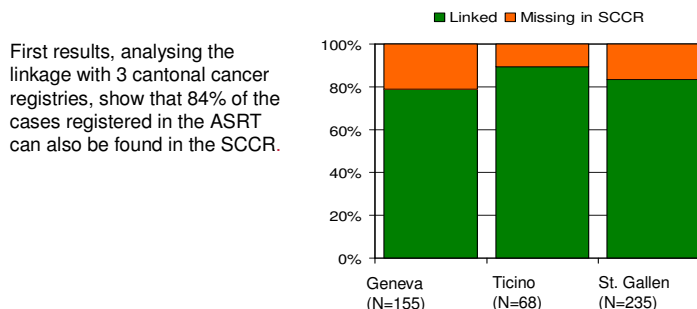
### References

- 1 Steliarova-Foucher et al.: Cancer 2005, 103:1457-1467  
2 Dal Maso et al., J Biomed Inform 2001, 34(6): 387-95

## Results

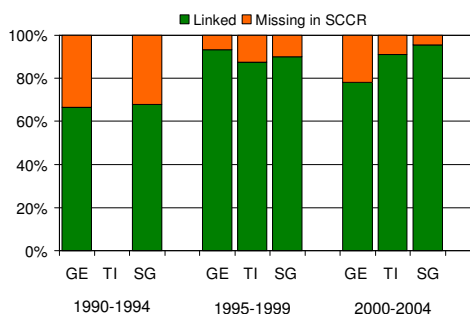
In the result section we show the successfully linked records per total number of records in the cantonal registry, including the datasets of the cantonal registries of Geneva / St.Gallen & Appenzell / Ticino. In a next step the datasets of the other 6 registries (Basel / Grisons&Glarus / Neuchâtel /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

### Linkage results: overall linkage rate\*



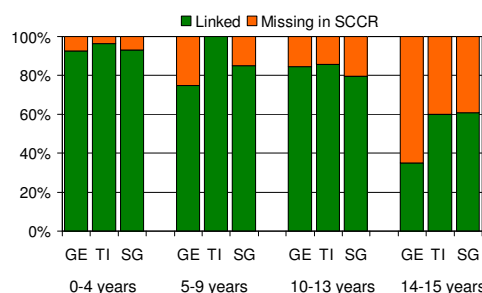
First results, analysing the linkage with 3 cantonal cancer registries, show that 84% of the cases registered in the ASRT can also be found in the SCCR.

### Linkage results: Year of diagnosis\*



Completeness 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

### Linkage results: Age at diagnosis\*



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.

\* children aged 0-16 years, resident in specific canton(s); with leukaemia, malignant solid tumours and all CNS tumours data of the cantonal cancer registry of Ticino available since 1996 (start time)

## Conclusion

- 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.